Re-Thinking Palliative Care in the Community

A CHANGE GUIDE

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PALLIATIVE CARE
INNOVATION

> **“You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die.”**
>
> — Dame Cicely Saunders
>
> nurse, physician, writer, founder of hospice movement (1918 – 2005)

How a 10-year Old's Personal Experience Led to His Quest for Holistic Palliative and End-of-life Care

Hsien Seow's mother died of cancer after struggling with the illness for four years. But not surprisingly, she wasn't the only one who struggled — the entire family was affected. Like all families of terminally ill patients, they watched her become weaker, and more frail, after each treatment. They watched as the disease took its toll, slowly taking away her independence and spirit. They watched her wither away, deteriorate in front of their eyes and, ultimately, die.

But much of the pain they endured could have been, should have been, avoided.

Never once during those four years did any of her doctors ever mention palliative care to the family. Never once did they mention that Hsien's mother could, or would, die. Never once did they ask about how she wanted to live out the balance of her life or where she wanted to die. Instead their focus was on the number of treatments she should have, the number of spots on her x-rays, her white blood cell counts. Science. Treatments. Tests.

Left unsaid was what really counted: Preparing both the patient and the family for what lay ahead.

At the very end of her life, as her breathing became more difficult, the family did not know where to turn for help — so they took her to the hospital. What they hoped and prayed would be a short stay lasted many weeks; and, instead of dying at home as she wanted, in familiar surroundings, with loved ones all around her, Hsien's mother died in a hospital bed. Any last wishes she may have had were left unfulfilled. And her family never had the chance for a proper good-bye.

As is often the case, our early life experiences influence the paths we choose to follow as adults. Today Hsien Seow is an Associate Professor in the Department of Oncology at McMaster University in Hamilton, Ontario and a Cancer Care Ontario Research Chair. He believes passionately that it is possible to improve how patients, and their families, live with serious diseases.

His recently-completed research studies, the results of which are outlined in this Guide, show just how promising the future can be. What also becomes evident is how much room there is for innovation when it comes to integrating our healthcare system, providing more holistic care and improving the quality of life, and death, for patients when they are the most ill, the most vulnerable and the most in need of our help.

Where We are Today

Because of the ever increasing numbers of both terminally ill patients, and the aging population, the world's healthcare systems are under tremendous pressure to provide *high-quality* end-of-life (palliative) care, *cost-effectively — despite a shortage of resources* on all fronts — be it trained health care professionals, hospital rooms, equipment or hospices. This situation will not change so collective thinking must.

Palliative care is dedicated to improving the *overall* quality of life for those facing life-threatening illnesses, by relieving symptoms and addressing psycho-social issues — not just for patients, but for their families as well.

Without it, patients can suffer uncontrolled pain and symptoms, depression, distress and poor quality of life. They can also be subjected to potentially avoidable hospitalizations and emergency department visits — which makes those in the last year of life the most expensive patients in the heathcare system.

A USUAL CARE DIAGRAM

And that's just part of the story. Between healthier lifestyles and advancements in medicine, people are living longer. Therefore, increasing numbers of older adults are living with, and dying from, multiple chronic conditions, which places yet another burden on the struggling healthcare system; and adds to the demand for palliative care.

Palliative care *can* occur in every setting. But because hospital and acute care centres are already overcrowded, and more and more patients prefer to receive care and die at home, policymakers are focused on enhancing palliative care services in the community. Research shows interdisciplinary palliative care teams — including family physicians, palliative care physicians, nurses, homecare workers, psycho-social advisors, bereavement counselors, clergy and pharmacists — working in homes and communities *do* improve care and *do* make a positive impact on the lives of both patients and their caregivers.

B INTERDISCIPLINARY TEAM CARE DIAGRAM

Compare **B**, where care is co-ordinated between all involved team members to **A**, where everyone works independently and the patient has to navigate the system alone.

The Harsh Reality

In the current environment (usual care) end-of-life home care services can be fragmented, with quality that's often inconsistent. Not surprising given all the variables, factors and numbers of providers who may, or may not, be involved with each patient.

So the result is, these patients, and their families, very often end up having to navigate the system as best they can on their own — with little coordination between all concerned. Fact is, every community across the province of Ontario is still struggling to implement palliative care teams in their communities in effective, accessible and sustainable ways. More high-quality research is needed to learn how to do it.

> **"We have no doctors here who are really interested or really know anything about palliative care or doing home visits or home care. Nobody is trained in that way."**
>
> — Tom, husband

Research Methods

Study Teams

To best understand *how* to develop a community-based palliative care system, well-established (2+years – 3 decades) exemplar models were sought.

A total of 11 interdisciplinary, community-based teams were found throughout the province. Although there were some differences between them, common characteristics included core teams made up of physicians, nurses and other providers with the expertise to provide homecare, both directly to patients and, indirectly, in consultation with others. All provided 24/7 service to patients and their families.

There was also an opportunity to study 4 newly-developing teams who were testing various interventions in an effort to strengthen collaboration between organizations to improve palliative homecare. They consisted of: The homecare service coordinating body (CCAC) and the service provider organizations (nursing, PSW, etc.)

Established
Brockville and District Hospice Palliative Care Service, South East LHIN
Cambridge Palliative Care Team
Central LHIN Palliative Care Team
Guelph Palliative Care Team
Kitchener-Waterloo Palliative Care Team
Niagara North Palliative Care Team
Niagara West Palliative Care Team
Pain and Symptom Management Consultation Service
Stedman Palliative Care Outreach Team, Brantford ON
Temmy Latner Centre for Palliative Care Team, Toronto ON
Upper Grand Palliative Care Team
Wellington Palliative Care Team

Newly-developed
*Central West LHIN
*Hamilton Niagara Haldimand Brant (HNHB LHIN)
*Mississauga Halton LHIN
*Toronto Central LHIN

*Sites tested more integrated care in smaller geographic areas within their Local Health Integration Network (LHIN)

Approach

A qualitative approach was used to gather evidence, develop insights and, finally, to answer the research questions. Data collection involved in-depth, semi-structured, in-person interviews with 124 providers and administrators from all 15 teams. Protocols and tools they use were identified. Both the data collection and analysis occurred in 2013.

Interviews

Core team members were interviewed, in addition to a cross-section of community nurses, personal support workers, family physicians, palliative care physicians, allied health professionals, palliative care consultants and service managers who work with the team. The script asked about:

- Each respondent's role
- The evolution of the team
- Team structure and interaction with the ecosystem of players
- How their care differed from usual homecare
- Team communication with each other
- What teams do for patients at different trajectory points
- Family physician involvement
- Processes and tools used
- Both success and failure patient care stories
- Advice for developing and expanding the team model

Data collection and analysis

Each interview lasted from 1-2 hours. In addition to them being audio taped, there was a note-taker present to transcribe key messages. A number of activities were incorporated into the interviews to assist the interviewees to formulate their responses. Written output was collected and/or photographed. Key messages were transcribed on to post-it notes. A poster for each respondent, displaying their photo, background, interview activities and transcribed post-it notes was created.

A realist synthesis analytic method, which is well-suited to developing a deep understanding of complex interventions, was used. The goal, through careful review of responses, was to identify both the mechanisms by which the team interventions work and the contributing factors of success.

The synthesis of findings was an iterative and accumulative process, in which all research team members participated. Analysis progressed from consideration of the individual respondent, to their entire team, to all teams. The initial step was for our research group to review and discuss notes from each respondent's interview and then record emerging insights. We then synthesized these findings and developed insights by team. Finally all teams syntheses were compared and contrasted to derive collective key insights. Team leads and respondents were contacted during analysis to clarify information on an as-needed basis.

Where Do We Go From Here?

The results of this research study are offered as a guide for change:

- To help you avoid any of the myths, missteps or pitfalls others have encountered along the way
- To share 5 key lessons learned during the course of conducting this study that will lead to a better, more realistic path forward
- To share 4 tools that can be used immediately. Tools that can help make sure you don't waste precious time re-inventing a wheel that's already been invented
- To give you a better understanding of how to not just develop a regional palliative care team in the home and community, but to create a better one
- **And most important of all, to help you develop a regional hospice palliative care system in your community. To inspire you to get started, today!**

Who's this Change Guide for?

Regional planners

Health care providers

Policymakers

The public

> **“Without the team, the care would have been impossible. We would not have known what to do. And supported by the team, we felt like we did a good job.”**
>
> — Loren, daughter

Re-defining Quality Care

1

What matters most for end-of-life care is...

- Reliable, accessible, patient-centered approach in the location of the patient's + family's preference.

WHERE WE STARTED

Do Teams Reduce Emergency Department Visits and Hospitalizations?

The care delivered by many interdisciplinary community-based palliative care teams exemplifies patient-centred care at its best. Anecdotally the teams say they are providing better care *and* helping to keep more patients at home, compared to those only receiving usual end-of-life homecare.

> But how do we define, track and measure the quality of care? How can we identify, and measure, the added value delivered by community palliative care teams?

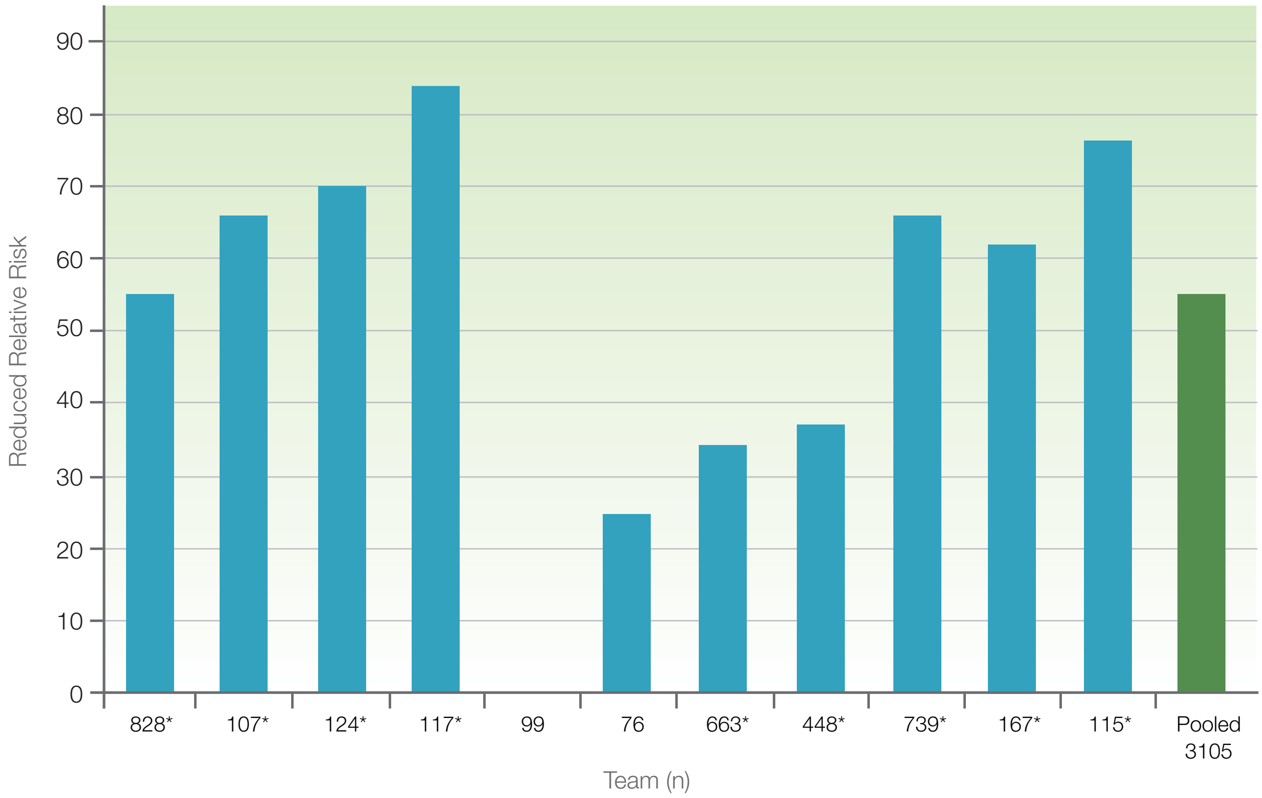
Research literature is filled with studies using metrics such as high rates of Emergency Department (ED) visits and hospitalizations in the last, few weeks of life and high acute care costs overall, because they are indicators of aggressive medical care.

> However Dr. Seow's study was one of the *first* to look at Ontario data, across multiple palliative care teams in the community. Eleven (11) established teams of different sizes, geographies and role combinations were examined.
>
> Results showed that, as compared to a matched group of patients receiving usual end-of-life homecare, those patients under the care of palliative care teams had a 30% lower likelihood of being hospitalized and/or having ED visits in the last two weeks of life. They also showed they had a 50% lower likelihood of dying in a hospital.

While impressive, this only concentrates on the teams' effect on hospital avoidance and health service use.

It quickly became apparent that once it was determined that the interdisciplinary teams had a positive effect on lowering utilization, it was important to know *why*. In other words, there is a major gap in the current body of research -- describing how the teams work together and how they are organized to deliver care.

Reduced Risk of Dying in Hospital When Receiving Interdisciplinary Palliative Care Team versus Usual Care



*statistical significance

WHERE WE ENDED UP

What Do Teams Do To Improve The Patient and Family Experience?

Speak to any provider, caregiver or patient and you learn quality care is not about big picture numbers. It's about individual experiences.

- Therefore, shouldn't defining "quality" begin by understanding how the care is addressing people's most important needs — what the impact is on both patients and their families?

KEY LESSON #1

Focusing on Patients Ultimately Results in Improved System-Level Outcomes

The research confirmed that teams spent the vast majority of time providing good care and helping patients remain at home — if that was their wish. The by-product of this focus on high-quality, proactive care was good system-level outcomes, such as lower ED visits and hospitalizations.

Sometimes hospitalizations were appropriate and necessary. Other times, teams proactively managed complex symptoms so patients could be kept comfortable at home. It was driven solely by continuous monitoring of what was appropriate for the patient and family.

What the 100+ interviews taught us:

- All providers were deeply committed to their patients
- High levels of care led to good system-level outcomes
- The key actions taken by providers each day could be summarized into the short list of commitments described below

TOOL 1

7 Quality Commitments to Patients and Families

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

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

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

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

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

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

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

KEY LESSON #2

There Are Many Different Ways to Fulfill The Quality Commitments

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

- Ensure patients and caregivers clearly know who this first line of contact is, and how to reach him/her
- Endeavour to resolve urgent situations quickly and effectively by phone, but be prepared for home visits by appropriate providers when necessary
- Build 24/7 capacity in the community — eg, liaise with patients' family physicians to clarify roles regarding on-and-after-hours responsibilities. Also coordinate with community family physicians and nurses to build a local team of palliative care experts who are willing to be on-call
- Supply education, guidelines and live support to frontline providers, including physicians and nurses, whenever needed, so their expertise improves and they can resolve crises on their own
- Make expert Nurse Practitioners extensions of community physicians, so the burden of answering calls and making house visits is reduced
- Have a roster of physicians who are willing to take on orphaned patients

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

- Cultivate genuine relationships between the providers — they know each other, and their capabilities
- Joint visits strengthen communication and build capacity
- Sharing patient information and insights daily reduces assessments, communication gaps, overlaps and misunderstandings — and avoids relying on patients for information
- Coordinating care across the system may not always be the responsibility of the core team, but they are there when needed, to keep things on track and to ensure patient care remains constant
- Ensure teams update each other when a patient crisis occurs
- Hold weekly rounds to review changes in patients' conditions, problem solve and prevent issues, share knowledge and support each other

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

- Providers are in constant or daily communication
- Nurse triages urgent calls, to determine who needs to respond
- Core team supports extended team to provide direct care, but remains within arm's reach of the patient or their family
- Having many eyes (including homecare nurses and personal support workers) on the patient/caregiver leads to a better understanding of the patient's true condition
- Teams keep track of patient even if they move to a different care setting, such as the hospital
- Collaboration and trust between physicians and nurses means prescriptions can be written or changed as needed, and quickly
- Hold weekly case rounds to knowledge share, support each other and attend to, or prevent, urgent issues
- Patient crises teach team members how to either respond more quickly or prevent similar situations from occurring in the future

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

- Understand every patient is unique and strive for customized care
- Step outside the boundaries of medical care with interdisciplinary teams who combine clinical and psycho-social expertise, to support a broad range of patient and family needs
- Red-flagging potential problems, pre-weekend, can prevent after-hours crises and, potentially, suffering
- Recognize when patients and families need/could benefit from other types of support, and broach these sometimes difficult subjects with ease
- Appreciate that the family, in addition to the patient, is part of the unit of care; and, therefore, attempting to deal with difficult family dynamics that might impede meeting patient needs, can also fall to the team

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

- Caregiver teaching and coaching
- Referring early helps build a supportive relationship and builds capacity before rapid decline begins
- Leverage providers' collective knowledge of the patient's current condition in order to minimize surprises, conflict and avoidable crises
- Set the right expectations to anticipate the physical and emotional process of dying

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

- Ensure logistical/legal side of death/affairs is organized
- Help realize special wishes
- Make time for psycho-social involvement — help patients and families reach a state of acceptance, dispel fear and anxiety, resolve conflicts
- Psycho-social support continues for bereaved family
- Group memorials held for families and health service providers give a sense of closure and honour

7. We will serve as an advocate so that you can achieve the type of care and death you desire

- Help families design care plan in advance
- Build good relationships with extended team, such as local care coordinators, and work together to manage difficult policy constraints
- Know the system, know how to cut through bureaucracy and help patients access different community services quickly
- Help patients transition into different care settings — i.e. hospice — by being the bridge/connector
- Plan pronouncement of death to ensure quick removal of the deceased

KEY LESSON #3

Quality Commitments Also Have Immediate Benefits for Health Service Providers

Provider experience is, arguably, just as important as patient and family experience. If providers don't see a benefit, convincing them to work differently will be an uphill battle. After reviewing the benefits to patients and families they identified as being the same for the health service providers:

- Not feeling alone
- Having an expert team for support
- Not having to ask for, or repeat, the patient story time after time
- Having integrated communication
- Less distress and suffering from provider grief
- Emotional and professional support from colleagues
- Feeling prepared, organized and highly functional
- Improved job satisfaction and sense of personal accomplishment, because they are able to fulfill patient and family wishes

The emotional strain and deeply personal and unpredictable nature of working in the field of palliative care can cause even the most dedicated professionals to burn out. Having practices that make delivering care easier, more efficient and more fulfilling is critical to creating sustainable models.

Overall, providers who worked in a fulfilling and effective way engaged and encouraged family physicians in their communities to get involved and become members of the extended teams. This helped build palliative care capacity and increased knowledge in physicians and other homecare workers which, in turn, meant these new team members began to mentor other providers in the community.

KEY LESSON #4

Quality Commitments Have a Role Outside the Home and Community

It's worth noting that emergency departments and hospital avoidances are not mentioned in the seven quality commitments. This is because avoiding emergency department visits is a result of high-quality care, but it is not the foremost goal. Instead, achieving the quality commitments is the primary goal, as they are the foundation of excellent, compassionate care, and they demonstrate both what's involved in achieving them and the benefits for patients, families and providers — regardless of where they might be practiced.

TAKE AWAY

Don't focus solely on system-level indicators. Instead, focus on the tangible quality commitments that improve the patient and family care experience. This leads to a win-win-win situation (patients, providers and health care system).

Re-thinking Ideal Models of Care

2

WHERE WE STARTED

What is the Best Model?

There is compelling evidence to prove community-based interdisciplinary palliative care teams help reduce potentially unnecessary health care services. Which begs the question, “Which model of care works best?”

Each of the fifteen (15) teams in this study had various models of care and physician involvement. Prior research on this topic was led by Dr. José Pereira, Ottawa University. It showed there are three main models which describe the roles specialized palliative care providers, including palliative care physicians and specialized nurses, play to support the family physician, homecare nurses and other community-based providers:

1. **Consultation:** The family physician has full responsibility for care-related decision-making. The specialist provider 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 specialists are no longer involved in the patient’s care.

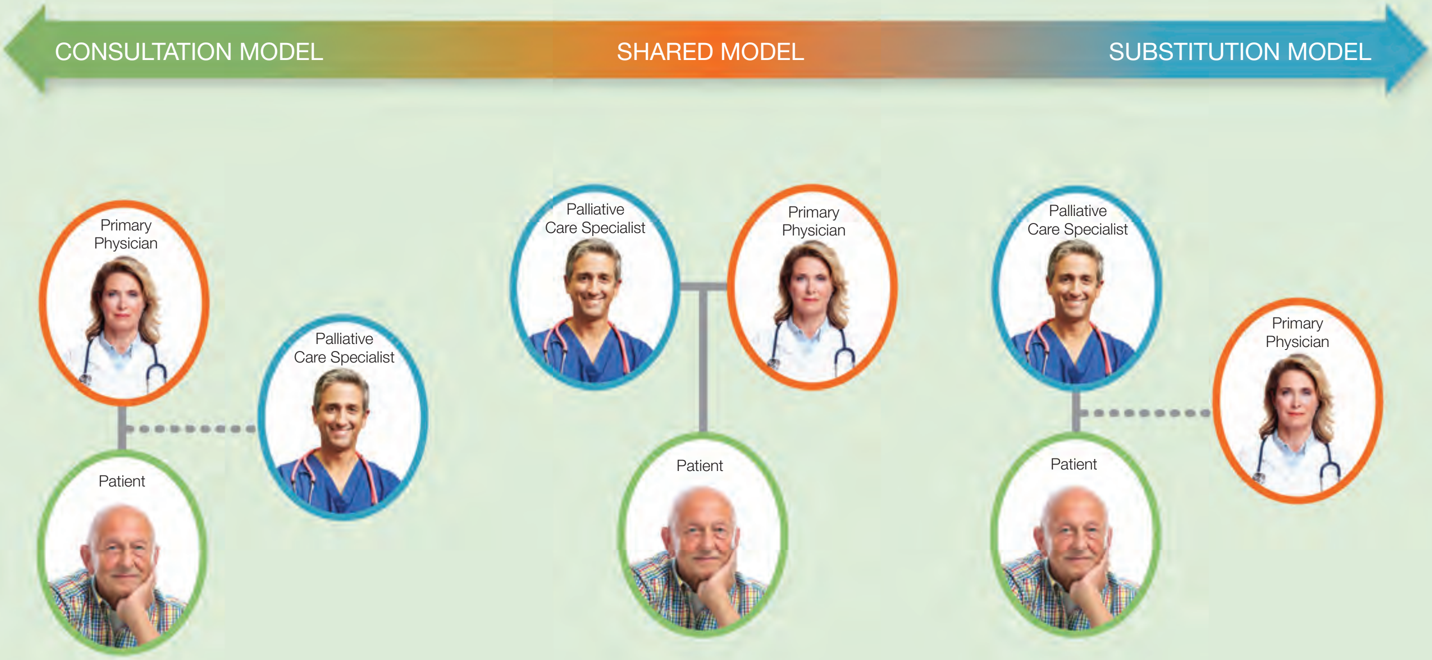
2. **Shared Care:** Decision-making responsibility is shared between the family physician and the specialist provider. The specialist focuses on all palliative care needs and continues prescribing related prescriptions on an as-needed basis. The specialist also continues to make regular patient visits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

3. **Substitution:** The family physician becomes peripheral and is no longer involved in the patient’s care. The 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.

The original assumption was one of these models would lead to better outcomes than the others. Thus the question was, “What’s the best model to duplicate?”

Results, however, showed that despite having different models of family physician involvement, virtually all the teams helped patients die outside of hospital, and also avoided Emergency Department and hospital visits at the end of life. So, could it be that there is *more* than one “best” model?

What also became clear during the interviews was that the specialists and family physician are only a few pieces of the broader eco-system of players. Several key factors influenced the model of care in each region.



WHERE WE ENDED UP

What Works Best in Each, Particular Community?

In the process of seeking answers to that question, several key lessons were learned.

KEY LESSON #1

Teams Work Across all Models

A significant learning was that the “teams” worked across all three physician models. Also interesting was the fact that while some teams may have worked in one model most of the time, that model *could* change, depending on patient needs. For example:

- If the patient lacked a family physician (orphan patient)
- The family physician’s or homecare nurses knowledge of palliative care
- Community resources at that point in time

Other teams regularly worked in all three models — either because patient needs varied very often and/or they worked within a diverse geographic region, with varying levels of provider and physician support and expertise.

In other words, there really is not one, best model. And teams work across *all* models.

Not to be Understated, Nurses Played an Essential Role in Virtually Every Model:

- Nurses were often the glue between physicians and homecare workers
- Nurses’ availability is more flexible than physicians, which made them vital for sustainability and scalability
- Nurses’ training and background personifies relationship-building, being part of collaborative teams and spending more time with patients one-on-one — all *critical* skills

KEY LESSON #2

All Teams Exist Within a Larger Ecosystem

Teams interviewed consistently stated that they worked with a core team, which was sometimes funded or housed by one organization.

For example, one core team, housed in a residential hospice, included a Clinical Nurse Specialist, a palliative care physician and a psycho-social spiritual counselor. But they also worked closely within the broader community ecosystem, which included the CCAC care coordinator, home care nurses, personal support workers, family physicians and more. The most mature core teams were very clear about working within a broader community team, responsible for quality patient and caregiver-centred care.

However, the core team did often play an essential role in developing and advancing the community team, because:

- They provided a critical mass of expertise
- They supported capacity and knowledge-building
- They often acted as the communication hub across settings and providers
- They cultivated a system-wide culture of high quality palliative care

Therefore the conclusion was, the core team is part of a broader ecosystem, crossing organizational boundaries to deliver quality care to the patient and caregiver. No one member is the only provider in the system. And understanding how to work together is essential in order to prevent burn-out and build capacity and long-term sustainability.

Together, *all* members in the broader ecosystem attain all 7 quality commitments.

KEY LESSON #3

The Team is Not Defined by Its Composition, Size, Housing or Funding

The fifteen teams studied varied considerably. They weren't defined by whether or not they had a hospice or worked out of one; or by how many palliative care physicians they had. There was a wide variation in the team size, the roles that comprised a team, as well as where they were housed.

For some teams, being housed in one place, like a hospice, helped galvanize them. For others, being virtual made more sense so they could span large geographies. The funding arrangements for team members also varied considerably.

Therefore, the secret to success was not whether they were housed in a particular place, had funding from one organization or had a special composition of team members. Instead, what was universal was, they all provided the same quality commitments. Which proves standardization in quality care is achievable — *without being constrained by a cookie-cutter approach*.

Diversity of Core Team* Composition and FTE at Time of CIHR Study

TEAM	PALLIATIVE CARE PHYSICIAN (FTE)	NURSES (FTE)	OTHER TEAM MEMBERS (FTE)
Brockville	6	2	4.7
Cambridge	1	2	1
Central Southlake	1	8	2
Champlain	1.3	3	1.7
Guelph	1	1	0.6
Hospice Niagara	0.5	1	0.2
Kitchener Waterloo	2	2	1
Niagara West	0.6	1	2.5
Stedman	3	3.5	5
Temmy Latner Centre	11.5	1	5.9
Wellington	2	2	1.2

KEY LESSON #4

The Team Needs to be Built on Local Community Strengths and Assets

The fact that no two teams are alike is best explained by the fact that no two communities are alike — which is the reason why, to be successful, it is paramount for every region to develop a local model that fits its own, specific strengths and weaknesses.

The secret to successful teams was that they were home-grown and started by building on the *existing strengths* of the community; and, over time, evolved to build new capabilities and relationships, to address previous weaknesses. Teams survived and thrived precisely because the context of local community was foremost in their development.

Therefore, it's okay that every model is unique. No teams are alike, nor should they be. You cannot, and should not, replicate another model. You have to develop *your own*, regional team.

Through the interviews several important factors were uncovered. Analyze them to help you build on existing strengths and also to adequately consider the context of your local community. It can play a significant role in the creation of your team's organizational model:

- ➜ **Level of physician involvement:** Can range from having many to having no family physicians with an interest in palliative care or willingness to make home visits, to the number of palliative care physician experts in the region
- ➜ **Extent of the nurse's role:** Can range depending on the number of nurses (clinical nurse specialists, nurse practitioners, nurse educators, etc.) available, their skill levels and engagement and relationships with other partners in the ecosystem
- ➜ **Size of geography served:** Ranged from a small local community, to a medium or large city area to a very rural area
- ➜ **Composition of additional palliative care expertise available:** Can include pharmacists, psycho-social spiritual workers, clergy, bereavement counselors, social workers, etc.
- ➜ **Availability and location of team's home base:** Sometimes teams worked out of a physical building where all members convened each day, others worked virtually
- ➜ **Funding model and stability for all team members:** Often members were funded by different organizations/funding schemes, sometimes one member was funded by multiple sources
- ➜ **A clear core focus and mission:** Some teams were exclusive to hospice-eligible patients, some only for those receiving CCAC services, some served those without a palliative care physician, while others had a broader mandate to serve any patient in the community

TOOL 2

The framework of factors affecting the palliative care model for your community

Community Asset Assessment for Palliative Care

Extent of the Nurse's Role

Level of Physician Involvement

A Clear Core Focus and Mission

Funding Model & Stablity for all Team Members

Availability and Location of Team's Home Base

Composition of Additional Palliative Care Expertise Available

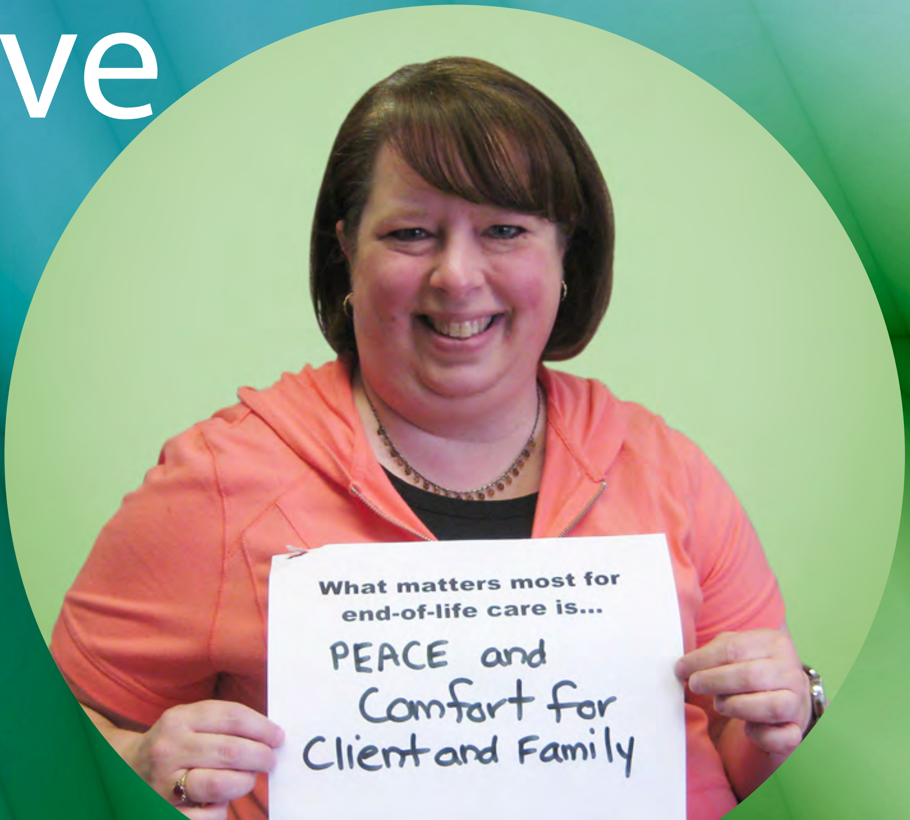
Size of Geography Served

TAKE AWAY

There's no winning formula. A community-grown model built on your local strengths and assets works best; and you can achieve standardization, without a cookie-cutter approach. Every region can have a unique team!

Re-Examining What Makes Teams Effective

3



WHERE WE STARTED

What are the Best Tools and Processes for Delivering Palliative Care?

The desire to identify, and replicate, everything that successful teams do makes good sense. So the expectation going in was, through this research, a set of “best practices” — optimal tools and processes, in other words — would be discovered. The desire was to identify the things all teams had, or did, in common that lead to particular outcomes, like supporting death at home.

What was learned, though, was that while some tools were essential for some teams, they proved to be unsuccessful for others. Not that this stopped any of the teams from delivering high quality palliative care to their patients. They all seemed to be functioning well.

How did they do it then?

WHERE WE ENDED UP

What is Needed to Build a Strong Team?

This model of delivering care is deeply relationship-based. Therefore, much of the success was the result of less tangible factors, relating to culture, attitude, communication and commitment.

While these aspects may be more complex from a scaling perspective, they truly represent the “magic”. A set of critical qualities distinguished strong, successful and sustainable teams from those who had the “hardware” and looked like a team on paper, but failed to truly collaborate and provide quality care.

KEY LESSON

The Secret to Success Wasn't About Tools and Processes

Despite not using the same tools and processes, all teams seemed to work efficiently and effectively. And when attempts were made to adapt them for use in other regions, it was clear it could sometimes help, but alone would not lead to success.

However what the 11 participating teams *did* have in common was a passion to improve palliative care. But 'passion' alone wasn't enough. In addition, the teams all had behaviours, practices and characteristics that contribute to excellence and success. They also had a special quality, a certain "PEP" that differentiated them from those teams who struggled or failed.

TOOL 3

The PEP framework of factors that make teams a success

PEOPLE	ENTREPRENEURIALISM	PURPOSE
Trust	Flexible/Adaptable	Shared vision/Sense of responsibility
Communication	Continual improvement	Holistic approach
Mutual respect	Seamless system navigation	Proactive
Flat hierachy		Education for health service providers

> **"The success of the team is entirely relationship driven"** — Clinical Nurse Specialist

PEOPLE

Trust

- Team development takes time and relationship-building occurs inter-professionally and inter-organizationally. Open communication leads to deep trust of judgement and abilities between team members
- Trust results in problem solving rather than laying blame. Team members are gracious with one another, they don't jump to negative conclusions if a patient is in distress and they believe each team member is competent and did the right thing. They meet and talk in an effort to better understand what happened at the previous visit
- Trust between team members and the Care Coordinator, helps streamline some of the bureaucracy
- Team members also earned the trust of the community. Without strong community family physician support the teams can't grow and thrive. The physicians are the key to timely referrals, establishing trust with patients and families and building palliative care capacity beyond the bandwidth of the team

Communication

- Because teams are relationship-based, interpersonal communication is not only the key to better patient outcomes, but to stronger, more effective, cohesive and happy teams. Even the best tools and processes can't replace the interactions necessary to build relationships and trust between home care providers.
- Successful teams focus on purposeful, informal communication rather than tools and formal, process-driven communication. It's not about filling out forms for the sake of it. Nothing beats the speed and directness of good, old-fashioned phone calls or texts.
- Reality is, no sites have electronic medical records (EMR) that are shared across all the organizational boundaries involved in providing care. So instead of expecting ideal communication tools and systems, virtual teams and their dispersed members rely on constant informal and interpersonal communication.
- Strong, close and constant communication, which includes community providers, allows all team members to overcome role confusion, build on each other's work, avoid duplication and provides patients with better continuity of care. Constant communication allows for proactive planning

and decreases the burden on patients for information sharing. The common conflict of "turf wars" is eased or resolved because teams are seen as supporting, rather them competing or challenging home care nurses and other health service providers. The extended team is able to follow patients and provide seamless transitions as they move in and out of different care settings.

Mutual Respect

- Team members value one another for the different expertise, experience and perspective they contribute. They see the roles as interdependent and themselves as a cohesive unit. This sense of "team" permeates across organizations, from the core to the extended team.
- Mutual respect fosters inclusiveness and accessibility. Teams didn't expect other health service providers, or other stakeholders, to come to them. Rather, they took a "we'll meet you where you are" attitude and approach. They reach out to, and accommodate community health service providers, making it easier to participate in patient care and palliative care knowledge sharing. Everyone's opinions and observations are valued because they all contribute to better patient care.

> **"During rounds we let the homecare nurses share first, because we know they have shifts to get to, and also aren't paid to attend, either."** — Clinical Nurse Specialist

Flat Hierarchy

- Typically in the medical profession there is a strong sense of hierarchy — i.e. doctors have the most training, nurses shouldn't challenge, etc. In these teams, however, there was a conscious effort to break them down, because they can become barriers to open communication and cooperation. Teams had flat organizational structures, placing equal value on each role, regardless of profession, education level or which organizations they belonged to.

> **"… it's a flattened structure … we're all on the same level … there's no hierarchy."** — Family Physician

ENTREPRENEURIAL

Flexible/Adaptable

- Team members were willing to be chameleons and fill gaps. They understand their scope of work is not pre-defined by expertise. They are open to serve and respond to varying patient/caregiver/health service provider needs
- Teams were very resourceful and solved problems and issues creatively and entrepreneuialy. They are given the autonomy to work outside the box to go above and beyond for their patients. Their bootstrapping mentality allows them to thrive without comprehensive resources, and to respond in a timely manner
- Guidelines were used as guidelines, not rules. They used their clinical judgement and also advocated to note exceptions to the rules if and when they were not in the best interest of either the patient or family

> **"We're the chameleons. The family shouldn't be the chameleon. We're the chameleon. The family knows the patient best and should be at the bedside with their loved one. We support them to do that."** — Supportive Care Clinician

Continual Improvement

- Teams had a desire to continually prove their worth and value to patients, families, funders and their community; as a result they continually strived to improve the patient experience. They had a clear hunger and sense of urgency in their work
- Teams used open conversations and feedback loops rather than metrics and pre-determined quantifiable measures. They continued to learn from experiences on a regular basis, by talking to each other and through conversations with patients/caregivers.
- Quality improvement happens both formally and informally. The teams don't make a project out of quality improvement, they just do it. Instead of worrying about science they use measures that make sense and that they can collect easily such as: The reduced number of frantic calls received from providers ... the increased complexity of the questions received as a sign of improved capacity ... and the decreased number of after hours calls received as a sign of good coordination and proactive planning
- Teams embrace interdisciplinary group problem solving and use their communication platforms (rounds), as an opportunity to learn together and make improvements in care
- Teams seem to never give up. They never accepted the status quo and even mature teams are still evolving and improving. Despite failing before they succeeded, what's important is they kept trying and didn't repeat the same mistakes

Seamless System Navigation

- Teams believe they have a role to play in helping patients, and their families, navigate the larger system during critical times of need and change. Patients and caregivers know any door (phone number) is the right one
- Providers help patients and families access, and get, what they need, protecting them from as much complexity as possible
- Teams help manage transitions. They follow patients wherever they go, being sure to fill in gaps in communication, whether it's on their end or from others. They make the effort to coordinate within and beyond the health care system, as needed by patients

PURPOSE

Shared Vision/Sense of Responsibility

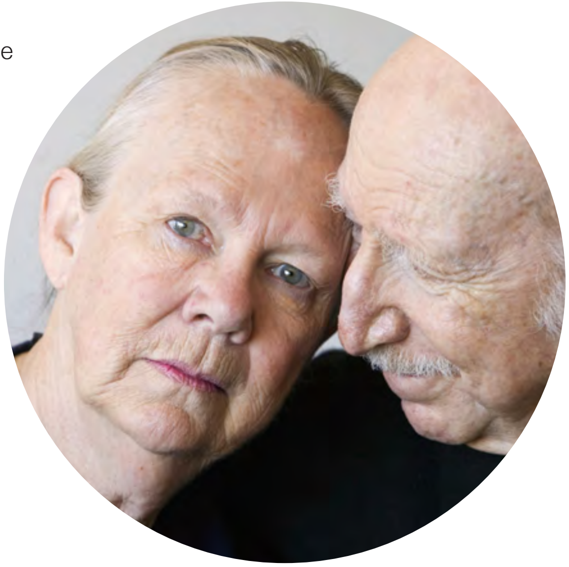
- Teams have a common, patient-centred vision that guides all they do — from governance to bedside care. They can clearly articulate why they're doing what they're doing so it makes sense to the community
- Teams' sense of duty was not defined or limited by roles. Members have a shared sense of responsibility for patient outcomes. They help one another identify and solve problems, rather than delegating/passing issues on by domain or expertise
- Their shared vision helped move them beyond bureaucracy. A unified commitment to do what's best for the patient empowers them to be creative problem solvers and flexible. They aren't encumbered by system rules, barriers and shortcomings.

Holistic Approach

- Teams believe quality palliative care is about more than pain, system management and emergency department avoidance. It requires an interdisciplinary approach to patient and family wellbeing
- A holistic approach also means the teams' commitment often moves beyond medical care, to include psychological, social, spiritual and grief and bereavement support, and more

Proactive

- Teams anticipate patient and caregiver needs, proactively planning with them for care
- Teams believe strongly that the proactive approach to care provides a foundation for a good death, and helps to avoid crises. Teams anticipate clinical issues before they arise
- By setting expectations for death, the teams aim to prevent it from being an emergency situation. It also helps prepare the care unit for end-of-life



Education for Health Service Providers

- Capacity-building is a core tenant of the teams' mission, because they realize they cannot provide good care alone. The more skills and knowledge within the broader ecosystem, the more effective the team can be; and the more patients they can serve
- Many teams see their jobs as working themselves out of a job. Teams believe they are a safety net and offer dependable support for other health service providers. It is not their intent to be the "star experts". They are there to be "best supporting members", and to help family physicians and others develop the capacity to provide high quality palliative care. Sometimes this occurs as joint visits with physicians or homecare providers, for training at the bedside. When a team is involved, the capacity of the community health service providers usually increases over time
- Capacity building also includes peer support. Teams create formal and informal opportunities to come together and share experiences and challenges. Most hold bi-monthly rounds which are open to the extended team, and partners. They're key to building capacity, providing mutual support for difficult cases and obtaining multiple perspectives on patient and family needs. Constant peer support and a more intimate sense of camaraderie alleviates the burnout that's part and parcel of the taxing nature of palliative care

> **"The main thing is, we're totally devoted to this model of care — whole person care."** — Psycho-Social Clinician

"I know we're doing a good job because ... the family physicians have developed the confidence to manage more of their less complex palliative care patients themselves." — Palliative Care Physician

TAKE AWAY

Despite each team being different, what was consistent across them all was "PEP". It was an essential ingredient to their success. "PEP" stands for people, entrepreneurialism and purpose. Every one of these components was critical to succeeding, sustaining and spreading.

Re-evaluating Measures of Progress — What's Realistic and What's Not

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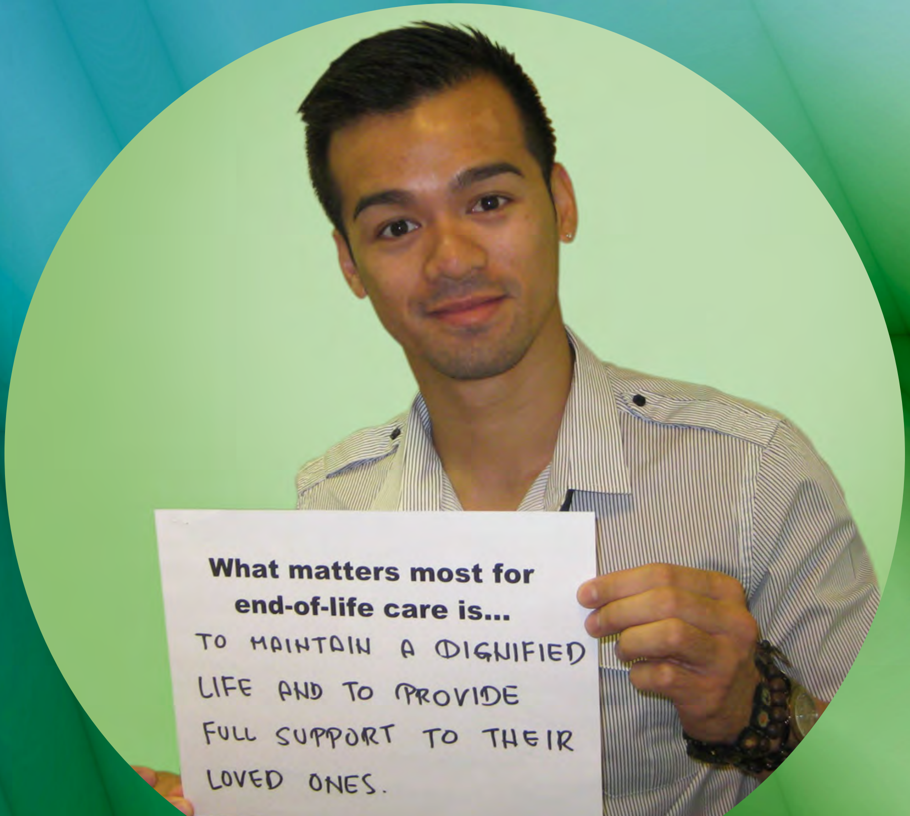


What matters most for end-of-life care is...

TO MAINTAIN A DIGNIFIED LIFE AND TO PROVIDE FULL SUPPORT TO THEIR LOVED ONES.

WHERE WE STARTED

What Quality Indicators Should be Used to Track System Change?

Life today is all about measurement, outcomes and quality indicators, and there's no doubt they're important. Many indicators are useful for helping organizations improve and track progress.

It was assumed that the teams being studied in this research would have been under a lot of pressure to demonstrate improved results quickly, year after year. So it was expected that they would have a concrete list of measures they tracked regularly, with ready data sources and clear reporting channels.

Not so.

The building of a community-based team — with all its complexities regarding people and change management ... complying with regulation and rules ... and providing actual care — was much more of a "trial by error" and "fly by the seat of your pants" process.

Quality measures *were* valued. But there were not any validated, or widely-used palliative care indicators used in the communities. Instead of waiting until such a set existed, they got started anyway — *less* focussed on choosing the right measures and collecting the data — and more intent on doing the right things for patients right in front of them.

That being said, the teams *did* measure things: They *could* count processes or outputs, but were unable to measure quality easily. However it was quickly realized that their measures of success evolved and grew over time. They may have started by measuring the number of patients they saw, but that grew to include the number of patients who required after hours help, the number of potential emergency department visits avoided and where patients died.

In the beginning measurement was more purposeful than perfect. As they matured, measurement became more formalized, structured and integrated into the broader system. It was clear it took a long time for the teams to truly mature and develop, that the evolution of the teams over time was directly related to the activities and measures of success used.

WHERE WE ENDED UP

What Should be Measured, When?

The establishment of community palliative care teams is an iterative process. Because these teams are based largely on relationships, it takes time — a long time — to build the long-term trust and communication necessary for successful and sustainable teams. They learn and adapt as they grow, refining ways of working together and serving patients and their families. Teams go through different phases of evolution, each with unique sets of opportunities and challenges.

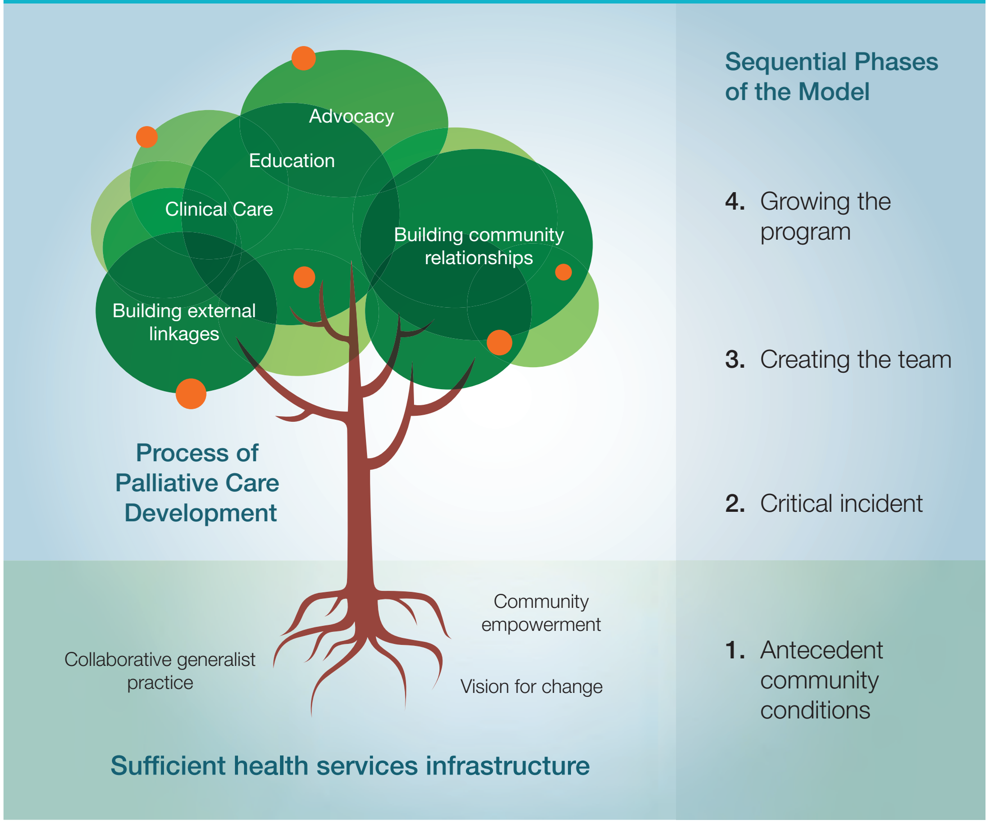
KEY LESSON

Measures of Impact Have to be Assessed Based on the Team's Developmental Evolution

Understanding team evolution from a phased approach helps identify *relevant goals and appropriate objectives*, for where the team, and the community, are in their journey of development. It also helps planners better anticipate and set expectations for how teams may evolve. For instance, a team in the early stages of establishing themselves in the community should not be expected to deliver the same outcomes as a team already deeply embedded in their local palliative care ecosystem.

To best capture the most common evolutionary phases of teams, a framework was created. Not intended to be an assessment tool, it's more of a "growth chart" — designed to help navigate progress, identify potential milestones to aim for — resulting in appropriate outcomes.

The Mary Lou Kelley Model



This is not a definitive standard; each team will have their own trajectory and unique points.

The knowledge gained during the research with the shared care teams was consistent with the model Dr. Mary Lou Kelley, Lakehead University, created to represent the development of palliative care in rural communities (see previous page).

Building on the Mary Lou Kelley Model — Framework of the Evolution Process of Teams

Inception	Start-Up	Growth	Mature
"The community has a dream to fulfill."	"Not fully functional, still proof-of-concept."	"Figuring out how to expand offering and build capacity."	"Integrated into the community."

Building on the Kelley model, in Tool 4 (see next page) non-rural teams, additional details per stage, milestones and potential measures of progress teams can strive for, were added.

TOOL 4

Framework of the evolution process of teams and appropriate outcomes

	Inception	Start-Up
Summary Statement	"The community has a dream to fulfill."	"Not fully functional, still proof-of-concept"
What's Happening	Local champion has a vision for improving palliative care. Begins building necessary infrastructure, resources and relationships through grassroots efforts.	Founding members begin to build team and ways of collaborating. They define and market services offered to patients and providers
Key Opportunities	• Build on existing palliative care relationships/network in community • Build local intelligence for a better understanding of needs, gaps, assets and what will succeed/fail • Create foundational relationships for a strong core team	• Develop effective ways of sharing info amongst team and broader ecosystem that is not dependent on common electronic medical record • Build rapport with community providers • Build an understanding in community of the team's role and how they can support providers • Outreach to upstream partners in the community, to encourage timely referrals and collaboration
Key Challenges	• Building team and buy-in cannot be top down. Team foundation must be built on grassroots relationships, before resources can be applied • It takes time and patience to build relationships • Obtain funding or find creative ways to maximize existing funding	• Maintain flexibility as team develops and fills local gaps. • Avoid turf wars with local homecare nurses and HSPs • Manage patient caseload with limited teams members • Lack of PC-trained local home care nurses and/or physicians • Work towards providing 24/7 care • Get referrals from physicians and hospitals • Secure enough funding to sustain team through start-up
Milestones	• Complete a needs assessment: Identify existing PC infrastructure, untapped capacity, what unmet needs can be served, and how to more effectively use resources • Articulate a shared vision of team and how to connect to community • Start to build buy-in from key stakeholders and providers in the ecosystem • Determine the offering to complement what exists — not compete	• Assemble core team of essential roles, including nurses and physicians • Practice the culture of a patient-centred mission and vision during decision making and problem solving • Establish team processes such as communication tools and methods • Create open ongoing dialogue of pain points and successes
Potential Measures	**Environmental Scan** **Perceived gaps in care:** service inaccessibility, service bottlenecks and inefficiencies, communication gaps **Taking inventory:** existing infrastructure, potential alliances, and resources including expertise and funding opportunities	**Team and Program Formation** **Formative (administrative) data:** caseload, patients seen, ED visits, urgent calls, home visits, doctor visits, bereavement contacts, professional consults, triage statistics, referral sources and destinations, place of death **Tracking process progress:** Identify most responsible physician, orphaned patients connected with a doctor, patients' end- of-life preferences (including place of death) documented, advanced care planning, ongoing patient monitoring, physicians providing 24/7 care **Tracking relationship formation:** perceptions of "team" collaboration, conflict resolution, power equity, role clarity, communication

Growth	Mature
"Figuring out how to expand offering and build capacity."	"Integrated into the community."
Stable core team with established relationships works to expand reach.	Team is trusted and valued. Seen as hub for knowledge-sharing and expertise.
• Make all core and extended members feel part of the team • Build palliative care capacity among health service providers • Gain providers' trust by working side by side to support and educate them • Form partnerships with community institutions and leverage opportunities to share resources (i.e. hospice)	• Deliver seamless continuity of care between settings • Continue to build capacity of community providers • Advocate for growth of palliative care network, ecosystem, and resources in community
• Find/hire compatible team members to work in dynamic environment • Build a critical mass of providers who feel comfortable addressing palliative care needs with minimal help from the team • Do the most with a mix of full-time and part-time team members • Manage travel and serving large regions with limited headcount • Get more referrals, earlier in patient trajectory • Find additional funding and resources to support growth	• Prevent team member burnout • Manage team turnover • Maintain role clarity and integration with CCAC and other partners • Manage changes in health service provider contracts and policy changes • Maintain continual sources of funding and resources
• Team has established local role and dependable partnerships • Able to offer 24/7 care • Work towards a full suite of compatible roles (nurse, spiritual care, PC specialist, CCAC) • Serve more patients	• Successfully building community's health service provider palliative care capacity • Health service providers understand when/how to best utilize and involve team • Effective feedback loop with patients and families • Team helps strengthen entire palliative network in community
Spreading Quality to more Patients **Formal capture of patient experience:** Start to collect and assess patient and family experiences: care need being met, preferences (including place of death) recorded and met, caregiver burden, provider continuity **Adverse incidences:** urgent calls not responded to in a timely manner	**Health System Measures** **System outcomes:** Acute care use, acute care death, end-of-life emergency department use and re-admission rates, palliative care admissions to hospital deemed inappropriate (alternate level of care beds) **Remaining gaps in care:** Palliative care at patient diagnosis, length of time in team's care before death

> **“It felt a little bit forced to have certain outcomes in certain buckets”.**
>
> — Administrator, Home Care Agency

TAKE AWAY

Following system-level outcomes too closely early on is setting yourself up for failure. Instead, use measures appropriate for your stage of development in your community. Celebrate these small successes at each stage, to stay motivated, build momentum and grow your program.

Re-inventing the Wheel is Unnecessary — Learn from Others

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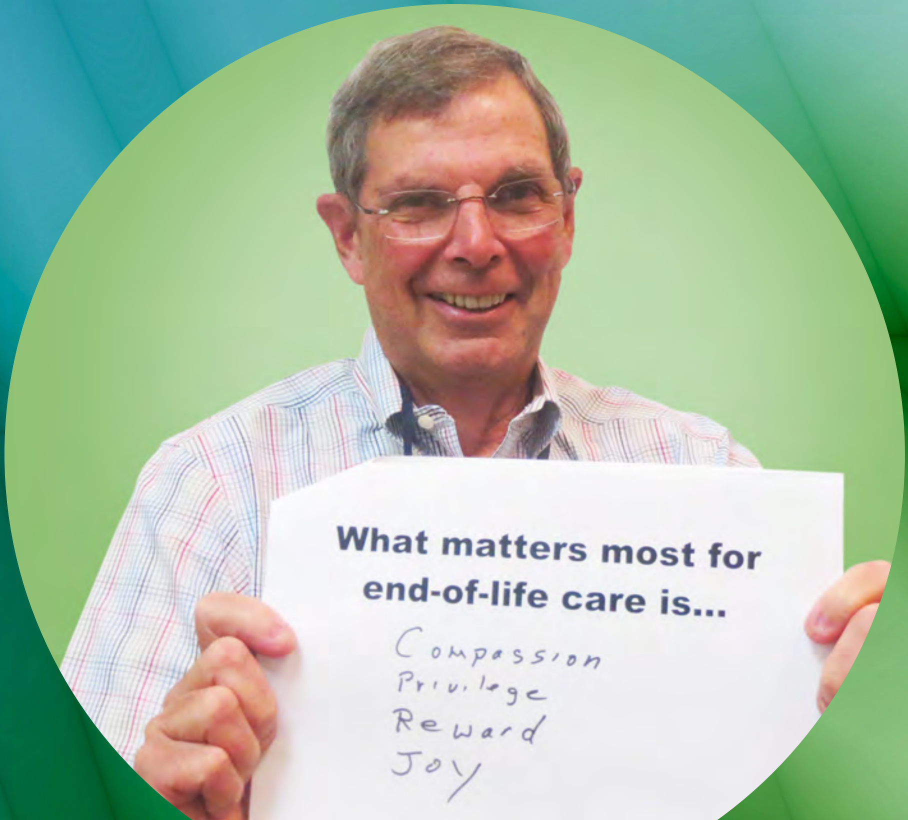

WHERE WE STARTED

How Are System Barriers Overcome?

The current "system" is not ideal. In fact, it is sometimes a nightmare to navigate and to work within. The reality is, there is a long list of complex, systematic barriers to face when attempting to improve care involving high-level policy changes, such as:

- Reimbursement
- Incentives
- Funding allocations
- Human resources, etc.

And the list goes on. However, established teams found a way to work within and around those barriers. The question was, "How did they succeed, sustain and sometimes spread — despite having to overcome a long list of system barriers?" Their responses were very interesting:

Although they wished for a better system, they didn't let the lack of one stop them. They found a way to work *around the bureaucracy* and barriers, *the very same system, in fact, that exists throughout the province*.

WHERE WE ENDED UP

How Did You Start *Despite* System Barriers?

What was interesting was, they often had different solutions to the same barriers. They used the same resources, but each used them differently. They used guidelines as guidelines — not rules — and never gave up or were willing to accept barriers to delivering patient-centred quality care.

They had no magic bullets. They may have had some better collaborators, but that was because they invested in building relationships with decision-makers.

KEY LESSON

You May Not Have All the Answers Now. But Collectively it's Possible

Provincial champions from existing teams are available to provide advice. Take advantage and learn from them, so you aren't re-inventing the wheel. There are an infinite number of barriers, some not yet thought of. All the answers will never be known; and it's clear that, because every community is unique, there is no one-size-fits-all solution.

Therefore, the best way to support both new and existing teams is to connect them with the leaders — the provincial champions who have lived through most of this already, and are willing to share the lessons they learned along the way. By connecting teams on the ground with established teams the best mentoring and advice can be provided in real time. And you can get off to a better start, more quickly and efficiently.

> As part of this study, various leaders from the established teams were asked some of the most common questions heard from others in the field. Once they have all been collected, and compiled they, along with a full list of FAQs, will be available at **www.palliativecareinnovation.com**

Here Are Just a Few

QUESTION: When trying to improve care delivery how do you move beyond naming, blaming and shaming?

RESPONSE #1: "We are a good team. When something does not work we look for ways to make it work. We do a lot of brainstorming and often quickly come up with a solution."
RESPONSE #2: "We all own our own errors and look at things from a systems approach — i.e. root cause analysis. This work is not easy, and although we hold one another accountable there is no benefit to looking for, and assigning, blame. We prefer to look forward — to what we can improve upon and how; and then we implement."

QUESTION: How do you know your team is doing a good job?

RESPONSE #1: "Feedback from the family. When we hear the family is happy with how their loved one died peacefully at home, without pain, with loved ones around them that tells us we accomplished what we set out to do."

RESPONSE #2: "Patients want to die at home; and most of them do that, comfortably. We follow up with the families afterward and they tell us things went as well as could be expected. If the opposite is true, we ask how things could have been improved, and thank them for the opportunity to learn. The team members are happy. That bodes well for good patient care."

QUESTION: How did your team improve care over time?

RESPONSE #1: "Communicate! We talk to each other daily, sometimes even on weekends. We relay information to one another so nothing falls through the cracks. We have a great system."

RESPONSE #2: "Use of technology is probably one of the best things. The bedside nurses know they can always reach one of us. If we need help from the ER, we call and tell them what's going on, exactly what we need from them and how we are able to continue facilitating care at home. We have access to Clinical Connect so we can see the hospital part of the patient journey."

QUESTION: What advice would you give developing teams?

RESPONSE #1: "Communicate with each other. Document as much as possible. Don't be afraid to ask questions."

RESPONSE #2: "Talk, talk and talk some more. Gets boots on the ground and meet others in the field. Make good notes, share them, follow up. Be clear to patients and families about who does what, and when. Don't dump issues, even if someone else dumped something on you. Just do it! Better to beg forgiveness, than ask permission sometimes. Hear the message, not the words. Talk some more."

TAKE AWAY

Teams used existing resources differently and found ways to overcome existing system barriers. The strategies they used were collected and compiled, along with their advice, to help you get on the right path, faster. What is also demonstrated is, *there is no right answer*, or a wrong one, for that matter, if it works in your community. There is a lot of hard work and determination required. But the champions across the province can, and want, to help you. You can learn from them. You are not alone.

Final Thoughts

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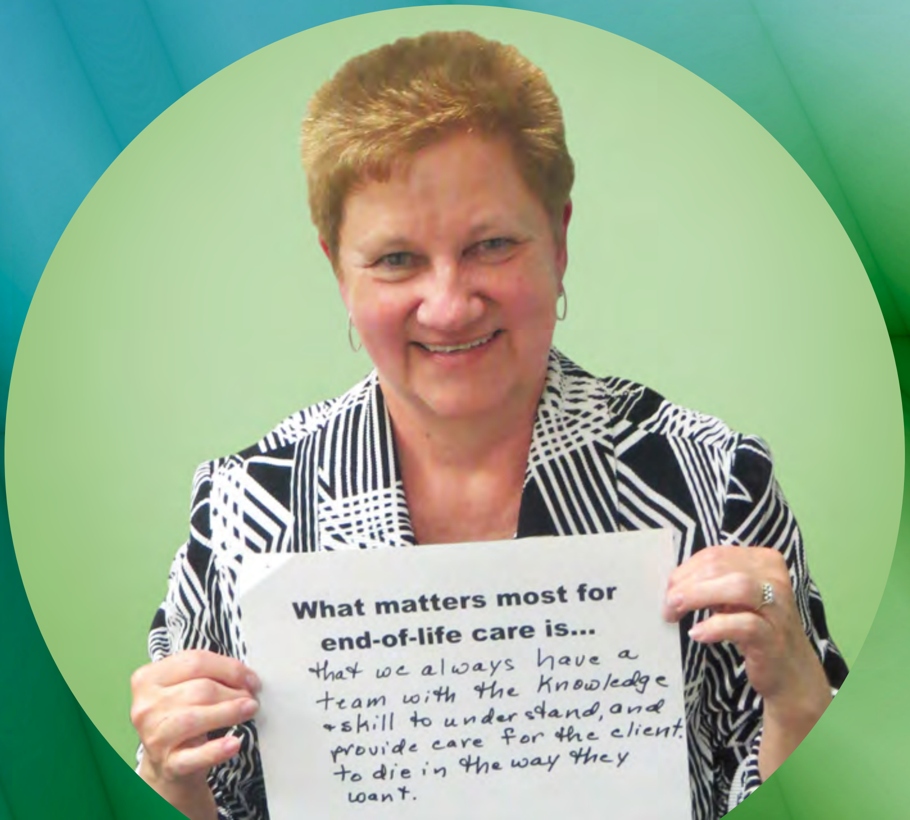

What matters most for end-of-life care is...

that we always have a
team with the knowledge
& skill to understand, and
provide care for the client.
to die in the way they
want.

As This Chapter Ends,
It's Time For Your Chapter to Begin

The fifteen teams have been studied, the results have come in and the research is complete. Hopefully the lessons learned and tools that have been born out of them will prove helpful to you, as you embark on your own journey.

There's no denying the path forward is not easy. It can't be when you're a trailblazer and an innovator, when you move in a direction no one's ever taken before. But there are champions and supporters in every community who can, and will, help you succeed in the quest for a high-quality palliative care system in *your* community — one everyone can be proud of, one that serves us all well when we need it the most.

A last piece of advice: As the research shows, you have the power to implement meaningful change, now. It's up to you, and your community, to unleash it.

Don’t Wait ...

1. For system-level indicators. The driver of change should be patient needs and quality commitments. While it will take time before the broader system as a whole is affected, you *can* start with improving care for the patients you see today
2. For the perfect model. All regions need to develop a unique team, based on their own community’s resources and assets
3. For the perfect tools to deliver palliative care. Communication and relationships will always be more important than tools
4. For new resources. Use what you have, differently
5. For the perfect plan, or to know it all before getting started. You will fail before you succeed, which provides the greatest lessons of all. Teams and the broader ecosystem are constantly evolving, changing and in a state of flux. You should strive to continually improve
6. For the perfect standardized pathway. Standardization *without* recognizing individual needs would be bad quality. Instead strive for customized standardization.
7. For electronic medical records (EMRs) to be the solution for communication gaps. Technology will never replace old fashioned, face-to-face or telephone conversations
8. For the palliative care expert to arrive. We are all responsible for basic palliative care knowledge
9. For the champion to emerge. You can become a champion. Many champions are needed
10. For someone else, such as policymakers, to eliminate the barriers and make the task easy. Working through bureaucracy in order to deliver a personalized care plan is not easy. Adapting to constantly-changing circumstances is not easy. Providing good patient care is hard work — it always has been and so it will always be

TAKE AWAY

You can do it now. Don’t wait. We can all work together, learn from each other and move the palliative care system forward. It must be done now because the health care system is failing; and the need for palliative care has never been greater.

Hsien Seow, Ph.D

About Hsien Seow, the Research Project Lead

Hsien Seow holds McMaster University's Cancer Care Ontario Research Chair in Health Services Research in the Department of Oncology. His Ph.D is from Johns Hopkins School of Public Health, Department of Health Policy and Management, with a concentration in health services research and a certificate in Gerontology.

His research interests involve innovating the palliative care system and improving quality of care. He has worked with RAND Health in Washington, DC, where he led health policy research, quality improvement and health advocacy initiatives. He earned a B.Sc from Yale University.

In addition to holding the Research Chair he is also an Associate Professor, Department of Oncology, McMaster University and is also Escarpment Cancer Research Institute Scientist.

After All is Said and Done ...

- We realized the path we originally set out to take, would not lead to a sustainable palliative care system and we needed to change course.
- We developed important learning tools to get us on the right path faster, and to share with others
- We believe we can build a better palliative care system by working together

We Wish to Thank ...

Research Coordinators: Deanna Bryant and Dr. Daryl Bainbridge

Innovation Researcher: Sue Tan

Research Assistants: Adrianne Van Dam and Wanda Oldfield

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All the health service providers and team administrators we interviewed, who serve as champions of palliative care in their communities and in the province. They are innovators and trailblazers in every sense of the word.

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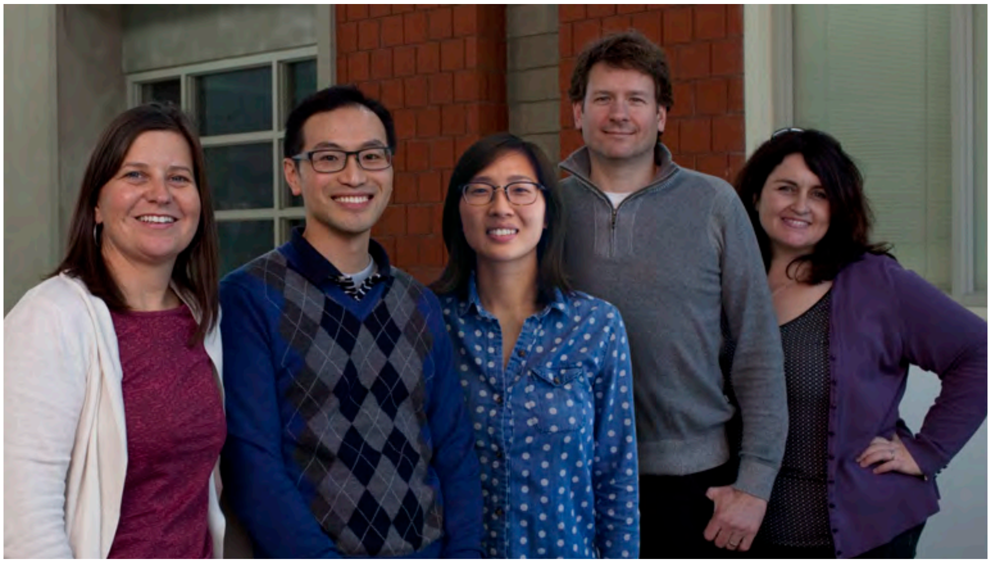
Editing: Fransi Weinstein

Finally, thank you to all the patients and caregivers who inspired us, and shared their stories, responded to surveys and let us into their homes and lives, in the hopes it would lead to demonstrable change. And all the providers we didn't interview, who are working hard, each and every day, to provide better palliative care.

We could not have done it without you.



L to R: Deanna Bryan, Hsien Seow, Sue Tan, Daryl Bainbridge and Wanda Oldfield

Dr. Hsien Seow's recently-completed research studies, the results of which are outlined in this Change Guide, show just how promising the future *can* be. It offers valuable information and useful tools to help you avoid the myths, missteps or pitfalls others have encountered. The hope is, it will help you understand *how* to build a better regional hospice palliative care system in *your* community. It is intended for regional planners, health care providers, policymakers, the public.

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