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Common care practices among effective community-based specialist palliative care teams: a qualitative study

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ABSTRACT

Objective Evidence has shown that, despite wide variation in models of care, community-based specialist palliative care teams can improve outcomes and reduce acute care use at end of life. The goal of this study was to explore similarities in care practices among effective and diverse specialist teams to inform the development of other community-based teams.

Methods Interviews with 78 providers and administrators from 11 distinct community-based specialist palliative care teams from Ontario, Canada were conducted. Interviews were audio-recorded, transcribed and analysed using an inductive approach to identify common themes.

Results 3 key themes across all teams emerged. First, the distinct models of care were generally summarised into 3 models: primary care and specialist providers either collaborated by transferring, sharing or consulting in care. Second, teams explicitly or implicitly followed 7 common care practices related to: specialised expertise 24/7; intrateam communication; timeliness; physical symptom and psychosocial–spiritual management; education; peace and fulfilment; and advocacy for patient preferences. Third, all teams emphasised the importance of team building, even more than using clinical tools and processes.

Conclusions Despite wide variation in models of care among community-based specialist palliative care teams, this large qualitative study identified several common themes in care practices that can guide the development of other teams.

INTRODUCTION

Expanding access to community-based palliative care is an important policy issue internationally because many patients prefer to die at home, hospitals are overcrowded and home care is often less expensive than hospital care.[1–4] Moreover, the rapidly ageing population will increase the demand for palliative care services at home. Over a dozen randomised controlled trials and dozens more observational studies[3 5–7] have shown that home-based palliative care can be effectively delivered using interprofessional specialist palliative care teams; the teams better managed symptoms, improved quality of life and prevented late-life hospitalisations than usual care. Yet, specialist palliative care teams in the community are not commonplace in Canada or in many other countries. This can be explained, in part, by the wide variation in the team models studied in the trials and a dearth of knowledge about which model of care is best. For example, some are led by specialist palliative care physicians, family physicians (also known as primary care physicians) or nurses and often include various other health professionals. Additionally, most trials focused on demonstrating the health services outcomes of the teams, but did not focus on describing the team's processes of care or on how they developed and sustained these teams. Thus, there is little knowledge on effective strategies to build and replicate optimal models of specialist palliative care teams in other regions.

A systematic review specifically examined the models of specialist palliative care, but could not conclude which particular model was the most effective.[8] Similarly, a meta-analysis that investigated the association between community nurse-led specialist teams and increased home deaths was also inconclusive.[9] The

challenges noted by both reviews were that few studies compared different team models, models were not described in detail, and studies were heterogeneous in measures and health systems. Addressing some of these limitations was a review by Bainbridge *et al*,[5] which examined the common components of 40 efficacious in-home specialist palliative care teams. It found the five most common elements were that teams had: (1) linkage to acute care, (2) a multidisciplinary team, (3) end-of-life expertise and training, (4) a holistic care approach, and (5) a pain and symptom management focus. However, the review noted that the original papers did not clearly describe the contextual relationship factors and the care practices that led to the effectiveness of these exemplar teams.

To address the above knowledge gap, we capitalised on a natural experiment existing in Ontario, Canada, where 11 regions independently developed their own community-based, specialist palliative care teams. The teams varied in team composition and geography served, but each had the five common elements found in the aforementioned review.[5] In a prior study, we demonstrated that exposure to these specialist teams was associated with a pooled 50% reduction in late-life hospital use and hospital death compared with usual community care.[10] We also examined each team individually: all but one showed a significant reduction in acute care use. This strongly suggested that the five common elements, which relate to processes of care and care practices, were more important in affecting outcomes than the various team models in which they practiced. However, neither their models of care nor their care practices had been described in depth or compared between teams. Therefore, we undertook a qualitative study on these previously studied 11 teams to understand their models of care and the care practices employed that led to their effectiveness at reducing end-of-life acute care use. Ultimately, this knowledge can guide the development of specialist palliative care teams in other regions.

METHODS

Study design and participants

In-person semistructured interviews were conducted with core team members (ie, providers and administrators) from 11 community-based specialist palliative care teams from Ontario, Canada between February and August 2013. These 11 teams were previously studied in a quantitative analysis.[10] They met the prior inclusion criteria of: being multidisciplinary team, having specialised palliative care expertise and training, providing care to patients in their homes, having linkage to acute care to prevent unnecessary admissions, and having a focus on pain and symptom management. In smaller teams (less than six members), all team members were interviewed. In larger teams, a purposive sample was taken to include interprofessional representation and those with the most experience with the team. Core team members interviewed included community nurses, personal support workers, family physicians, palliative care physicians, allied health professionals (eg, social workers and psychosocial–spiritual counsellors), specialised symptom management nurses, homecare case managers and team managers. The study was approved by the McMaster University Research Ethics Review Board.

Interview guide

The research team developed an interview guide based on the relevant literature, existing palliative care provision frameworks,[11–14] and expert opinion from multidisciplinary perspectives (see online supplementary appendix 1). The guide was designed to thoroughly explore participant's perspectives on the key care practices that led to the effectiveness of their team to provide community-based palliative care. In particular, they were asked extensive details of their model of care. Using a framework proposed by Pereira *et al*,[13] interviewees classified their team model into either: (1) substitution model, where the palliative care specialist providers take over the responsibility for care; (2) shared care model, where the specialist providers and family physician share decision-making; or (3) consultation model, where the family physician is responsible for care but seeks the specialist's recommendations for one-off issues. They were also asked about care practices, tools and processes used to deliver optimal palliative care. Based on responses, the interviewers followed up with additional or clarifying questions. Each interview was conducted by a pair of co-authors (HS, DBa, DBr, STT), with one as the primary interviewer. Each interview took 1–2 hours to complete. The interview guide was pilot-tested with 10 participants from the study sample to ensure feasibility and utility.

Data analysis

The analysis of the data and thematic synthesis was an iterative and accumulative process in which all the interviewers (HS, DBa, DBr, STT) participated. The unit of analysis was the team. The focus of the analysis was to identify the mechanisms by which team interventions worked and the contributing factors of success based on the providers, parts and circumstances that constitute each team.

A four-stage analytical process was used to synthesise the raw data into the findings.[15] First, interviews were audio taped and reviewed, with key ideas extracted by the primary interviewer and transcribed into a document for further analysis. One document was created for each of the teams in the study. Second, the interview questions and relevant conceptual frameworks were used to create a thematic framework for organising each team's data and the emerging ideas.[13 14] Third, emerging ideas were

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coded, compared and the common themes identified. Finally, themes were compared across all teams to identify and describe the overarching themes.

Throughout the analysis, any discrepancies between researchers' interpretation of the data were resolved through discussion until consensus was reached, with referral back to the original audio files and respondents (ie, member checking).

RESULTS

From the 11 teams, we interviewed a total of 78 palliative care providers and administrators, an average of 7 interviews per team (range of 4–10; see table 1). Participants represented multiple professions: nurses, physicians, administrators and others. Participants were mostly nurses (27%), women (83%), and in their role for more than 5 years (48%). Although structural differences were identified between the teams, commonalities were found in care practices and approaches to team building.

Differences between teams' models of care

Key differences among the 11 teams include the variation in geography, caseload size, median time on service, number of physician and nurse providers on team, and providers' funding sources (see table 2). For instance, the palliative care physician full time equivalent varied from 0.5 to 11.5. No two teams were exactly alike in structure. Moreover, most respondents strongly identified with one of the three team models in the framework:[13]

Four teams identified working mainly in the substitution model. Some of the respondents from these teams reported that in their communities, family physicians could not be depended on to provide quality palliative care.

> End of life care without the [specialist] team would be terrible. I'm not sure what people would do without us…Without us, there would be nothing. People would be just floating. Specialist physician

> The patient has had pain for years, the family physician isn't dealing with the problem, so we go to the [specialist] team. Community homecare nurse

Three teams worked in a shared care model.

> We get involved as long as the family physician in on board. Specialist nurse

> I know we're doing a good job building capacity because the requests I receive now as a palliative care physician…are for much more complex patients. That means the family physicians have developed the confidence to manage more of their less complex palliative patients. We're building capacity and working ourselves out of a job. That's the goal. Specialist physician

One team worked in a consultation model.

> It's our responsibility to be the go-to person to provide support to the care providers. Specialist nurse

> The team is an extension of me, [the family doctor]. Family physician

Three teams identified working in a mix of all three models, depending on the complexity of patient's needs and the comfort level of the family physician in providing palliative care. Overall, we found that each team's model of care depended on various factors related to the community context, such as the geography and the available expertise and interest of primary care providers. For instance, in urban cities, there were often more specialist providers, enabling these teams to work in a substitution model. In rural cities, teams were more often working in a shared-care model.

Common care practice themes

Besides model of care, we also investigated the teams' care practices. The respondents described many diverse care practices they undertook as a team to provide optimal palliative care. Our analysis summarised these care practices into seven distinct themes. We present each theme below and in table 3 provide a definition of each care practice in the form of a principle of patient care.

Specialised expertise 24/7

Respondents described critical care practices as having specialised training and experience and being able to access this round-the-clock. The palliative care patients they saw had conditions that could change rapidly; providing good care meant being accessible to manage those crisis situations and prevent unnecessary emergency department visits or hospitalisations. The expertise was either available to patients and families or to primary care providers, depending on the model of care.

> Some family physicians think they provide good palliative care, but shut down after 5pm…Patient symptoms don't shut down after hours. So it's important for patients to know who to call and what to do. Specialist physician

Intrateam communication

Respondents described the need for strong communication between members so that care was coordinated, efforts were not duplicated and patients did not have to repeat their story numerous times. Teams had both formal (eg, weekly rounds) and informal (eg, phone calls or hallway meetings) means to communicate with one another in a regular manner. Of note is that none of the teams had an electronic medical record that was accessible to all team members spanning different organisations.

Table 1 Participant demographics (n=78)

Participant characteristic	Nurses n (%)	Administrators n (%)	Physicians n (%)	Other* n (%)	Overall n (%)
Gender					
Female	20 (95.2)	18 (100)	9 (47.4)	18 (90.0)	65 (83.3)
Male	1 (4.8)	–	10 (52.6)	2 (10.0)	13 (16.7)
Number years in current role					
0–5	2 (9.5)	10 (55.6)	7 (36.8)	10 (50.0)	29 (37.2)
6–10	3 (14.3)	3 (16.7)	7 (36.8)	1 (5.0)	14 (17.9)
11–15	4 (19.0)	1 (5.6)	1 (5.3)	–	6 (7.7)
16–20	2 (9.5)	1 (5.6)	2 (10.5)	–	5 (6.4)
21–30	2 (9.5)	–	–	–	2 (2.6)
Unknown	8 (38.1)	3 (16.7)	2 (10.5)	9 (45.0)	22 (28.2)
Total	21	18	19	20	78

*Other included homecare case managers, personal support workers, spiritual and bereavement staff and data support staff.

Table 2 Differences between teams' models of care

Team	Geography	Number of decedents 2009–2011	Median time on service (days)	Palliative care physicians FTE (funding source)		Nurses FTE (funding source)		Other team members FTE (funding source)		Main model of care*
1	Urban	830	40	1	(FFS billing)	8	(Regional health authority)	2	(Regional health authority)	Substitution
2	Suburban	221	53	3	(FFS billing)	3.5	(Regional health authority)	5	(Community fundraising and regional health authority)	Substitution
3	Suburban	144	38	1	(FFS billing)	1	(Homecare coordinating agency)	0.6	(Homecare coordinating agency)	Mixed
4	Suburban	125	40	1	(FFS billing)	2	(Homecare coordinating agency)	1	(Homecare coordinating agency)	Mixed
5	Suburban	105	36	0.5	(FFS billing)	1	(Homecare coordinating agency)	0.2	(Community fundraising)	Shared care
6	Rural	90	63	2	(Alternative payment plan)	2	(Homecare coordinating agency)	1.2	(Local primary care team)	Mixed
7	Urban	676	45	11.5	(Alternative payment plan)	1	(Hospital and community fundraising)	5.9	(Physician's alternative payment plan)	Substitution
8	Suburban	497	49	2	(FFS billing and alternative payment plan)	2	(Homecare coordinating agency)	1	(Homecare coordinating agency)	Substitution
9	Urban	775	38	1.3	(FFS billing)	3	(Regional health authority)	1.7	(Local hospital)	Consultation
10	Rural	268	23	0.6	(Alternative payment plan)	1	(Homecare coordinating agency)	2.5	(Local hospital and homecare coordinating agency)	Shared care
11	Rural	181	32	6	(FFS billing)	2	(Community fundraising)	4.7	(Community fundraising and local hospital)	Shared care

FFS, fee-for-service, that is, physician bills for each aspect of care and service they provide according to a set price mechanism.
Alternative payment plan, that is, physician reimbursement is a combination of FFS and salary.
*We used Pereira's framework[13] which depicts a spectrum of models of care ranging from: (1) substitution (specialist provider takes on full responsibility for care and family physician is no longer involved); to (2) shared care (decision-making is shared between specialist provider and family physician); to (3) consultation (family physician has full responsibility for decision-making and asks specialist for advice on a particular issue).
FTE, full time equivalent.

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Table 3 Seven common care practice themes

	Care practice themes	Description as a practice principle
1	*Specialised expertise 24/7*	Provide dedicated expertise 24/7 so that the patient never feels alone
2	*Intrateam communication*	Communicate and connect as providers so the patient does not have to repeat their story numerous times
3	*Timeliness*	Respond in a timely and effective manner so that the patient experiences minimal discomfort and distress
4	*Physical symptom and psychosocial–spiritual management*	Attend proactively to the wellness of the patient's mind, body and soul so all forms of suffering can be alleviated
5	*Education and preparedness*	Provide education and guidance so that the patient can prepare for what lies ahead
6	*Peace and fulfilment*	Support the patient to resolve personal affairs and realise goals so that they can feel fulfilled, and at peace
7	*Advocates for patient preferences*	Serve as advocates so that the patient can achieve the type of care, and death desired

> Before the team, we would go in blind a lot of the time. We were like detectives…[Now] I physically have the information on each patient when I go out for visits…I am able to track Palliative Performance Scale, Do Not Resuscitate orders, etc. Homecare nurse

> When communication is lacking, the events can be tragic. Administrator

Timeliness

All teams described the importance of responding rapidly to unmet patient needs in order to prevent a crisis from occurring or react once a crisis has already occurred. Teams had care practices that supported rapid responses, such as triage systems, processes to access prescriptions quickly and coordinated communication channels so providers have the most up-to-date information from which to make decisions.

> The good thing about our team is we go to homes, assess the situation and implement—it happens right away. Specialist physician

> Being present in the time of crisis: that means more than how good I can manage your symptoms. Homecare coordinator

Physical symptom and psychosocial–spiritual management

Respondents discussed the significance of a holistic or whole-person care approach. Pain and suffering was clinical, and included social, emotional and spiritual aspects of care. As a team, they had to manage expertly pain and symptoms, and go beyond medical care and support a broad range of needs, which were often interconnected.

> At the heart of palliative care is pain and symptom management. And spiritual pain is very real even though…you can't touch it…Once we can control psycho-social issues, the pain is easier to deal with. Specialist physician

> The main thing is we're all totally devoted to this model of care—whole-person care.—homecare nurse.

Education and preparedness

Providing information so patients and families were prepared, reassured and had realistic expectations of the dying process was a critical role of the team. The teams were also proactive in their care management trying to avoid preventable crises, such as by flagging potential problem cases before the weekend when services were reduced.

> Education is a big part of crisis management. I always try to educate so patient and family know what to expect and not to panic…Most importantly I set up early supports for families so they have a plan. Specialist nurse

> When we are one step ahead of a crisis, there is no crisis. Community homecare nurse

Peace and fulfilment

Respondents mentioned that providing palliative care went beyond clinical tasks, and was also about helping patients and families find peace and closure. Supporting a good death meant understanding what the patients individual goals were and helping them fulfil final wishes, such as taking trips, getting married or asking for forgiveness. Spiritual care was viewed in a broad sense to include existential fulfilment.

> Spiritual care is about so much more than religion. It's where people find meaning in life. Spiritual counsellor

> We focus on living until you die, [we] don't focus on the dying…[we get them to be] free enough of symptoms to have a meaningful connection with loved ones. Homecare coordinator

Advocates for patient preferences

Teams standardised care practices yet were committed and flexible to best address the identified individual needs of patients and families. In essence, the teams standardised customisation. This was critical because achieving respect, dignity and control was unique to each individual. For instance, teams tried to support patients to die in their desired place.

> In doing hospice palliative care we realize that there really is no right way or wrong way to do this, there's just their way, which means it has to be patient and family focused…you realize every patient's need is different, care is tailored, so rules constantly change. Administrator

> We are chameleons…we shift to meet the needs of the patients…we meet them where they are. Spiritual counsellor

Different strategies to achieve common care practices

Though teams undertook the same common care practices (eg, providing 24/7 care, communicating with team members, etc), they accomplished these by different means. For instance, to address off-hour symptom exacerbations, some teams relied on symptom management kits in the home, whereas these kits were irrelevant in other regions where teams had access to pharmacists who would provide late-night home deliveries or in teams where specialist physicians were always available and carried medications on-hand. Similarly, there was no single tool identified that was common to all or even the majority of the teams. For instance, teams used different tools to measure symptom burden or functional change, such as the Palliative Performance Scale (PPS),[16] the Edmonton Symptom Assessment System (ESAS),[17] the Distress Thermometer[18] and the Canadian Problem Checklist (CPC).[19]

Common focus on team building

Despite differences in how they achieved the care practices, we found a common emphasis on team building, which was foundational to their ability to provide quality care. Team building consisted of the following relational aspects.

Trusting relationships

Respondents stated that team development took time and relationship building had to occur interprofessionally and interorganisationally. The presence of open communication—often constant and informal—was critical to building and maintaining trust, allowing team members to overcome role confusion, avoid duplication and provide better continuity of care. This helped build a deep trust in the judgement and abilities of other team members.

> The success of the team is entirely relationship driven. Family physician

> We trust each other to expose our own flaws, warts, and all. Homecare coordinator

Mutual respect

With trust, teams developed mutual respect. This respect meant that when issues arose, they would focus on problem solving, not laying blame. Respondents stated they learned to value one another for the different expertise, experience and perspectives they each contribute. They saw their roles as interdependent and themselves as a cohesive unit.

> We see everyone as equals and work together as a team; otherwise we will fail. Specialist physician

Flat hierarchy

Respondents often stated they had rather flat organisational structures and placed equal value on each role. They made conscious efforts to avoid hierarchies, since they were viewed as barriers to open communication, effectiveness and timeliness.

> It's a flattened structure…we're all on the same level…there's no hierarchy. Community homecare nurse

> It's not about doctor or nurse. It's about someone who is engaged and is able to trouble shoot things, know what can and can't be done, knows how to make things happen…people who know how to morph into different roles, the fluidity of the roles within the community sector, whoever happens to show up at that point in time, nurses wearing doctor hats and vice versa. Specialist nurse

Support

Belonging to a team also provided members with moral support. This would help individuals to avoid burnout and compassion fatigue, as well as, enable the team to sustain and grow their model.

> Knowing at my lowest of lows, I can turn to my team members for support and help. Spiritual counsellor

> You feel you have a safety net…We feel like a team. Administrator

> If a nurse has an issue, such as a hard time contacting the family physician, she'll call me and tag team. We can problem solve. As a result everyone is more proactive. Specialist nurse

DISCUSSION

Our qualitative interviews with 78 specialist palliative-care providers revealed that teams worked in one of three main models of care (substitution, shared care or consultation), yet were otherwise unique in their geographies, team compositions, etc. They all shared seven care practices: specialised expertise 24/7, intra-team communication, timeliness, physical symptom and psychosocial–spiritual management, education, peace and fulfilment, and advocacy for patient preferences. While there was variation in which clinical tools were used among teams, all teams emphasised the importance of team building. To the best of our knowledge, this is the largest study on multiple community-based specialist palliative care teams that compares their care practices in depth to one another.

We found each team's model of care strongly reflected local community partnerships and existing assets. For example, smaller and rural communities had few specialist providers, and thus the involvement of primary care was more critical. That teams used various strategies to achieve common care practices demonstrates the customisation of existing resources to the local context, which is critical to successful implementation.[20] This is also consistent with prior

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research[21–23] on community capacity development in palliative care validated in rural and First Nations communities (ie, located on lands identified by the Canadian government as reserves). The implication for developing other teams is that there is no one best model. The most effective model of care is built on local community strengths, provider relationships and includes implementing the common care practices identified in this research.

This study expanded on prior research by examining care practices and interpersonal factors of specialist palliative care teams. To advance the development of future teams, our findings suggest that the interpersonal and human factors related to team building, such as trust and mutual respect, need dedicated time to develop, aligned incentives, and deliberate support. Overall, our study findings are similar to the results from an international expert panel that sought to identify key strategies for developing the best palliative care models.[24] Our study supports this expert opinion by using a large sample size with multiple diverse teams and a more rigorous analytical approach that includes contextual relationship factors.

Strengths of this study were the large number and diversity of teams and the strong convergence of themes. Study limitations included not interviewing patients or caregivers to corroborate or refute statements from teams. The teams were all from one province, possibly limiting the applicability of the findings to regions or countries with a different healthcare structure.

In conclusion, this qualitative analysis of providers from 11 effective specialist teams identified seven common care practices for delivering home-based palliative care. These results suggest that similar care practices exist even among very diverse specialist teams with different models of care. Understanding these care practices can help to inform the development of other community-based teams.

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