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What is This?
Health system characteristics of quality care delivery: A comparative case study examination of palliative care for cancer patients in four regions in Ontario, Canada

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Abstract

Background: A number of palliative care delivery models have been proposed to address the structural and process gaps in this care. However, the specific elements required to form competent systems are often vaguely described.

Aim: The purpose of this study was to explore whether a set of modifiable health system factors could be identified that are associated with population palliative care outcomes, including less acute care use and more home deaths.

Design: A comparative case study evaluation was conducted of ‘palliative care’ in four health regions in Ontario, Canada. Regions were selected as exemplars of high and low acute care utilization patterns, representing both urban and rural settings. A theory-based approach to data collection was taken using the System Competency Model, comprised of structural features known to be essential indicators of palliative care system performance. Key informants in each region completed study instruments. Data were summarized using qualitative techniques and an exploratory factor pattern analysis was completed.

Results: 43 participants (10+ from each region) were recruited, representing clinical and administrative perspectives. Pattern analysis revealed six factors that discriminated between regions: overall palliative care planning and needs assessment; a common chart; standardized patient assessments; 24/7 palliative care team access; advanced practice nursing presence; and designated roles for the provision of palliative care services.

Conclusions: The four palliative care regional ‘systems’ examined using our model were found to be in different stages of development. This research further informs health system planners on important features to incorporate into evolving palliative care systems.

Keywords

Community health systems, evaluation studies, hospitalization, neoplasms, organizational case studies, palliative care

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Introduction and background

Individuals with incurable cancer represent the majority of patients requiring palliative care in the community.\(^1,2\) Improving the provision of this care is a stated objective of cancer care systems internationally.\(^1,3,4\) Over the last decade, gradual progress has been made in assessing outcomes of care at the patient–provider level as well as patterns of care at the system level, to help inform program development for those with advanced disease.\(^3,5\) Population outcomes, such as location of death and use of acute care services such as emergency rooms, hospitals, and intensive care units are common indicators that are proposed to reflect the quality of palliative care in a given region.\(^6–9\)

Geographic variation in the utilization of these health resources for end-of-life cancer patients have suggested possible disparities in access to quality palliative care. By examining administrative data at the population level, a number of population variables have been found to be important predictors of acute care service use, such as age, income, morbidity, and physician continuity.\(^6,10–12\) While these secondary data offer general insight into some antecedents of acute care use by palliative care cancer patients, these data do little to explain the associations between patterns of resource utilization and potentially modifiable health system organizational factors. Studies to date have not systematically examined the possible organizational quality factors that may lead to these outcomes of interest. Despite a number of palliative care delivery models having been proposed, often based on expert opinion, to address the gaps in palliative care at the process and structural levels, the specific elements required are often vaguely described.\(^13,14\) The purpose of this study was to explore whether a set of health system characteristics could be identified that might enable better population palliative care outcomes for cancer patients, such as less acute care use and a greater proportion of home deaths.

Health system characteristics that include capacity, access, and coordination elements represent potentially modifiable factors within the system that can reduce acute health care service use; these formed the framework for this inquiry.\(^15,16\)

Methods

Study design

A comparative, multiple case study approach was used, with four health care regions purposefully selected as single cases, representing the units of analysis. The phenomenon of interest in this study was the palliative care delivery system within each region in the years 2003 and 2004. At the time of the study initiation, regional health service utilization statistics were available for up to 2003, matched to our time of inquiry.

This study received approval from the Sunnybrook Health Sciences Centre ethics review board, Toronto, ON, Canada, prior to enrolling subjects.

Study setting and case selection

In 1993, the Ontario Ministry of Health and Long-Term Care (MOHLTC) began to address deficiencies in palliative care delivery by offering funding opportunities for four types of palliative care initiatives, namely: (1) education initiatives for interdisciplinary providers; (2) education initiatives for family physicians; (3) support and maintenance of residential hospice volunteer visiting programs; and (4) establishment of regional pain and symptom management teams. These initiatives targeted practice areas that were identified as key to improving palliative care in the community and long-term care sector, representing the only province-wide palliative care policy in existence in Ontario at the time of the study.\(^17,18\) However, the manner in which these funding opportunities were used in each health care region was at the discretion of the local planning bodies, resulting in different configurations of palliative care programs and extents of implementation.

Ontario is divided into 14 health care regions based on patterns of tertiary referral.\(^19\) Extreme case sampling\(^20\) was used in selecting four of these health care regions for study. The regions selected represent the lowest and the highest rates of cancer-related hospital acute care deaths and emergency department (ED) visits in the last two weeks of life, for both rural and urban settings in the province. These rates were determined from administrative data that has been reported previously.\(^6\) Sampling in this manner provides for a literal replication and contrasting of results across case types (i.e. high versus low performance on these indicators and urban versus rural), enabling the research team to identify common palliative care program patterns and unique issues in the health care regions. Table 1 displays the demographic characteristics of the regions selected. These four regions are indentified in this paper as Regions A, B, C, and D.

Conceptual framework

A search of the literature failed to reveal any existing applicable frameworks for examining palliative care systems.\(^21,22\) We developed a conceptual framework comprised of structural features proposed to be essential elements of palliative care system competency to guide the variable oriented analysis (see Figure 1). The framework was based on the empirical literature...
and consensus of experts, including health services researchers, palliative care nurses, and physicians, using a modified Delphi method. Key evaluative elements were derived from Alter and Hage’s framework for conceptualizing health system coordination, Ferris et al.’s Square of Care and Organization model of quality palliative care provision, a previous review of multiple models of palliative care provision reported in national research documents, and system competency indicators from the Canadian Hospice Palliative Care Association (CHPCA) national accreditation standards.

The three domains within the resulting adapted system competency framework were capacity, access, and coordination.
and coordination (see Figure 1). Capacity refers to the presence of all necessary resources, including office space, financial support, and a work force representing an adequate mix of disciplines and palliative care expertise. Access is the availability of system resources, expertise, and services to patients when these are required. Accessibility is maximized with minimal wait times, routine and standardized identification of patient needs, provision of 24/7 coverage and limited criteria for eligibility. Coordination was operationally defined as the extent to which the system is efficiently organized so that patients and information flow seamlessly within the system. Important precursors to coordination are the sharing of common assessment tools and protocols among providers, joint planning initiatives, tailoring of palliative care program implementation based on evidence from system needs assessments, inter-provider relationships, and the presence of a central coordinator role.

Data collection

Data were collected from each of the four health care regions using three sources: (1) in-depth, semi-structured interviews with key informants; (2) self-administered surveys completed by key informants; and (3) structured, detailed reviews of relevant program or system planning documents. We triangulated multiple sources and types (qualitative and quantitative) of data to increase the credibility of the conclusions based on a convergence of evidence. Data collection occurred in 2007.

Key informant interview and survey

The research team developed an inventory of all palliative care service providers and institutions within each region of interest, using existing local listings and input from regional palliative care administrative stakeholders. This inventory process utilized the following sources relating to palliative care: (1) profession association member lists; (2) provincial conference attendee lists; and (3) local group lists. Key informants were considered health care providers and/or administrators who had knowledge of the palliative care system for adult cancer patients in the health care region in the reference years (i.e. 2003/2004). The inventory was used to identify potential key informants and compile palliative care resources in each region. Additional key informants were identified using a snowball procedure. A sample of 10–15 key informants, representing a diversity of disciplines, was selected until data saturation (redundancy of themes during the interview) was achieved.

Data were collected from each key informant through both an individual in-depth, semi-structured telephone interview and a self-completed survey, respectively reflecting qualitative and quantitative measures of interest to the research team. These instruments (see Appendices A and B for question list) were developed through a consensus process with the research team, based on the theoretical constructs from the System Competency model and related items from a previous theory-driven evaluation of a supportive cancer care system in Ontario. The interview was designed to explore in depth the informants’ perceptions of key structures and processes that comprised the palliative care system in the region and its functional elements.

The survey was designed and revised with input from research team members to capture quantitative items, such as human resource counts and scaled system perception ratings. Both the interview and survey questions were pilot tested with relevant key informants outside of the study regions and modified accordingly to ensure that the questions adequately explored the phenomenon of study.

Key informants were asked to respond to telephone interview and survey questions pertaining to the state of palliative care delivery in their region in the reference years from 2003 to 2004. Telephone interviews were audio taped and transcribed verbatim. Following the interview, the survey was sent to the key informants to complete. A summary of items from the interview and survey are available in Appendices A and B.

Document review

All regional policy documents pertaining to service delivery for those at end of life in the regions of interest were reviewed and summarized. Relevant documents were identified through key informants, regional health councils, palliative care associations, institution libraries (e.g. regional cancer center), hand searches of the bibliographies of key documents, internet searches, and members of the research group. A data collection form was used to extract and summarize data from each document. All documents were reviewed by the research coordinator (DB) and checked for accuracy and completeness by a second analyst (DM).

Analysis

The conceptual framework provided the structure for the systematic analysis of the qualitative and quantitative data in the form of a variable oriented analysis. As prescribed, the case study data analysis took part in two major stages. The first step was to build an understanding of the relationships among factors within each case or region (i.e. within-case analysis). Once this was completed, a cross-case comparison
was made between the four case summaries to discern patterns (see Figure 2). Measures to promote rigor in case study research were followed, including adherence to a study protocol (i.e. manual of operations), use of a study database, organizing summary data into a factor matrix for analysis, and a documented chain of evidence to trace steps of evidentiary process.30

Qualitative data

The transcripts from the semi-structured interviews were analyzed to identify major themes in the domains of interest within each respondent, between respondents in each case (i.e. health care region), and finally between different cases. Domains of interest followed a template organizing style of data, as set out by the questions in the interview guide, with coding being primarily deductive.31 An editing organizational approach to content analysis was also employed, using an inductive coding method to capture any novel circumstances or emerging themes germane to the overall aim of the study.31

Study interviewers and coders were blinded to the classification of regions as having higher or lower acute care utilization patterns. All transcripts were coded by a primary (SD) and secondary coder (DB) to ensure accurate interpretation of the responses.32 Consensus was reached on codes and the coding system was revised accordingly as the analysis progressed. The data were extracted from the primary coder’s notes. Summaries by variable for each interview and each case were organized in a table format and incorporated into the overall study data matrix. The summary data notes provided by each of the analysts contributed to the audit trail regarding agreement in coding and analysis of the data.

Quantitative data

A Microsoft (MS) Access database with a data entry interface was designed for the survey data for error reduction purposes. Data from the surveys were entered into the database and examined for completeness. A data verification check was done on 15% of the surveys. A descriptive analysis consisting of frequencies and means was conducted. Responses to scaled questions (from the survey) were categorized according to the median score for each item for all respondents in a region. On these four-point scales, ranging from 1 = ‘Agree Strongly’ to 4 = ‘Disagree Strongly’, a median score below 2 for the statement was considered largely true (positive), above 3 was considered largely false (negative), and median scores in between (2–3) were somewhat true (somewhat positive). For survey or interview questions with open-ended or continuous response options, the following rules were applied in instances of conflicting responses among respondents in a region to a specific question, to determine an overall region response to that item. The most common response was accepted as the most probable depiction of this element in the region, except when at least two respondents, from different organizations, disagreed in the same manner with the common response. In this case, if there was a greater than 60% agreement in the region on a specific response then this was accepted as the most probable depiction of this element in the region. Otherwise, if agreement on a specific response was only 60% or less of respondents, then this question statement was considered as somewhat present/evident.

Using these rules, these data were summarized graphically in three tables that grouped capacity, access, and coordination items to give a visual array of regional responses for each item. These tables form the basis of a straightforward pattern analysis. For a given item within each table, cells were assigned to represent whether a feature/factor was ‘mostly evident’, ‘somewhat evident’, or ‘hardly evident’ for each region. Data from qualitative and quantitative sources that examined common factors were triangulated for an overall summary of each item of interest within the data tables. The interpretation of results followed the principals of outcome pattern matching, using an interpretative metasynthesis approach to conclude which features were present or absent for each particular region.33,34

Figure 2. Multiple case study analysis process.
Results

In total, 43 respondents were interviewed, representing a diversity of palliative care related disciplines (see Table 2). Key informants across the regions included 6 nursing case managers/nurses, 11 palliative care physicians, 15 managers or directors of community programs, and 1 academic. See Table 3 for the structural characteristics of the study regions.

Respondents were unanimous across the regions in reporting that home care services were rarely always available to patients when needed, nor responsive to all of patients’ needs. The lack of available nursing shift care was also consistently voiced. Significant barriers to accessing community-based palliative care services existed in all of the regions. The major weaknesses perceived in these communities’ ability to provide palliative care services were lack of funding, absence of a centralized, formal structure for coordination, and shortage of providers with expertise in palliative care. The presence of these limitations likely speaks to the state of palliative care in general at that time (2003/2004) in the province. It was noted in doing our analysis that there was at least one active demonstration project providing 24/7 interdisciplinary palliative care (e.g. in Region B) during the study time frame; however, the catchment areas of these programs only spanned part of their respective regions. Few respondents recalled whether a palliative care system needs assessment had been conducted in their community in the previous five years. Figures 3–5 provide graphic summaries for each domain within the system competency framework from the analysis of interview and survey data. Patterns emerged in these displays that appear to distinguish the state of palliative care delivery in each region. The absence or limited presence across the regions of many of the elements examined clearly illustrates the common deficiencies in palliative care delivery at this time. Still, there are resource and organization features within the domains of capacity, access, and coordination that suggest Regions B and D had more developed palliative care systems compared to Regions A and C. Regional differences are presented in detail in the following section for each of the framework domains.

Capacity

A key difference between the regions emerged within capacity, summarized as use of available funding in the development of palliative care service configurations. All the regions had access to palliative care specified resources from the four MOHLTC Palliative Care Initiatives; however, the extent to which this

<table>
<thead>
<tr>
<th>Region A</th>
<th>Region B</th>
<th>Region C</th>
<th>Region D</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total 10 respondents (4 survey respondents)</td>
<td>Total 10 respondents (5 survey respondents)</td>
<td>Total 13 respondents (12 survey respondents)</td>
<td>Total 10 respondents (9 survey respondents)</td>
</tr>
<tr>
<td>4 nursing case managers /nurses</td>
<td>3 nursing case managers /nurses</td>
<td>6 nursing case managers /nurses</td>
<td>3 nursing case managers /nurses</td>
</tr>
<tr>
<td>3 palliative care physicians</td>
<td>5 palliative care physicians</td>
<td>2 palliative care physician /oncologist</td>
<td>1 palliative care physician</td>
</tr>
<tr>
<td>3 manager /director community program</td>
<td>2 manager /director community program</td>
<td>5 manager /director community program</td>
<td>5 manager /director community program</td>
</tr>
</tbody>
</table>

Table 2. Key informant respondent’s designation from each study region.


<table>
<thead>
<tr>
<th></th>
<th>Region A</th>
<th>Region B</th>
<th>Region C</th>
<th>Region D</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer center(s)</td>
<td>0</td>
<td>2</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Hospitals</td>
<td>4</td>
<td>12</td>
<td>32</td>
<td>22</td>
</tr>
<tr>
<td>Residential hospices</td>
<td>2</td>
<td>3</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Long-term care facilities</td>
<td>23</td>
<td>39</td>
<td>43</td>
<td>15</td>
</tr>
<tr>
<td>Palliative care physicians (estimate)</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>4–5</td>
</tr>
<tr>
<td>Palliative care unit beds (adult)</td>
<td>23</td>
<td>154</td>
<td>7</td>
<td>22</td>
</tr>
<tr>
<td>University(ies)</td>
<td>0</td>
<td>2</td>
<td>0</td>
<td>1</td>
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</table>
funding was used differed across the regions. In Regions B and D, these initiative dollars were used in a more organized fashion to educate health care providers in palliative care and develop a pain and symptom management team. Evidently, there were proportionately more doctors and nurses with palliative care training in these areas compared to Regions A and C. Regardless, respondents from all regions indicated that resources to support palliative care delivery were inadequate to meet the needs of the population.

Access

Differences were found between the regions in access related to the (i) availability of after-hours service and (ii) mechanism through which palliative care patients were identified. Only in Region B did respondents state definitively that specialized palliative care services could be accessed on a 24/7 basis, even though in both this region and Region D there were community-based palliative care professionals, namely physicians, consult teams, and pain and symptom management teams that provided around-the-clock care. Respondents in all the regions indicated that those physicians who had palliative care specialization made house calls.

In Regions A and C, palliative care patients requiring support were most likely to be identified in hospitals and cancer centers by physicians, whereas in Regions B and D, these patients were identified through a combination of channels, such as in a specialized program or by family physicians, in Region B, or by independent providers, including family physicians, volunteers, nurses, or social workers, in Region D. Few of the respondents in any of the regions could confidently estimate the proportion of palliative care patients who had their needs routinely assessed.

There was consistency across respondents that family panic, caregiver fatigue, and an inability to cope with pain and symptoms contributed to hospital emergency room use for end-of-life cancer patients. In Regions B and D this was offset in part by the availability of after-hours palliative care in the community and the possibility of immediate transfer to palliative care designated in-patient beds. Finally, key informants in Region A affirmed that significant (longer than one week) waiting lists for palliative care services existed in their community, while Region D informants disagreed.

![Figure 3. System capacity indicators.](image-url)
with this statement, and those from Region B and C were mixed in their responses.

**Coordination**

Differences between the regions emerged within coordination related to (i) formal reporting structure, (ii) use of standardized assessment tools, (iii) designated roles, and (iv) location-of-death planning. Although the organization of palliative care in all the regions was fragmented to some extent without any formal coordination mechanisms, a well-organized, comprehensive program existed in Region B that provided services to a central catchment of this area. In addition, Region D had many informal networks and an implied chain of command despite having no central, formal structure.

Palliative care provision was largely sporadic in Regions A and C, whereas in Regions B and D specific pager systems were in place to provide 24/7 contacts for patients and health providers. In Region C, in most cases urgent access to a physician was only available by the palliative care patient going to the hospital emergency room.

The use of standardized assessment tools and a common in-home chart were evident to some extent in Regions B and D, but not in the other regions. In Regions A and C, service providers mainly communicated via the telephone and one-way fax referral.
<table>
<thead>
<tr>
<th>Place of death planning</th>
<th>Region A</th>
<th>Region B</th>
<th>Region C</th>
<th>Region D</th>
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</thead>
<tbody>
<tr>
<td>Home death consistently offered</td>
<td></td>
<td></td>
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<tr>
<td>Expected death planning (pronouncement/certification)</td>
<td></td>
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<tr>
<td>Routine practice to determine patient’s desired place of death</td>
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<table>
<thead>
<tr>
<th>System structure</th>
<th>Region A</th>
<th>Region B</th>
<th>Region C</th>
<th>Region D</th>
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</thead>
<tbody>
<tr>
<td>Palliative care system structured</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Extent of specialized palliative care provision in community</td>
<td></td>
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<tr>
<td>Overall satisfaction with the service delivery system</td>
<td></td>
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</table>

<table>
<thead>
<tr>
<th>Provider designated roles</th>
<th>Region A</th>
<th>Region B</th>
<th>Region C</th>
<th>Region D</th>
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</thead>
<tbody>
<tr>
<td>Service providers have designated roles/responsibilities for palliative care</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Use of acute care beds for palliative care avoided</td>
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<table>
<thead>
<tr>
<th>Standardized/shared policies</th>
<th>Region A</th>
<th>Region B</th>
<th>Region C</th>
<th>Region D</th>
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</thead>
<tbody>
<tr>
<td>Palliative care specific policies and/or standardized procedures shared between agencies</td>
<td></td>
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<table>
<thead>
<tr>
<th>Planning mechanism</th>
<th>Region A</th>
<th>Region B</th>
<th>Region C</th>
<th>Region D</th>
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<tbody>
<tr>
<td>Overall mechanism/forum for palliative care system planning/management</td>
<td></td>
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<tr>
<td>Palliative care needs assessment conducted within 1997 to 2002</td>
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<tr>
<td>Palliative care needs assessment used for implementation</td>
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<tr>
<td>Community’s capacity to provide palliative care monitored</td>
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<tr>
<td>Mechanism for monitoring shared throughout the community</td>
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<table>
<thead>
<tr>
<th>Coordination of care</th>
<th>Region A</th>
<th>Region B</th>
<th>Region C</th>
<th>Region D</th>
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</thead>
<tbody>
<tr>
<td>Mechanism to monitor the coordination of palliative care services</td>
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<tr>
<td>Sufficient outreach and information was provided</td>
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<table>
<thead>
<tr>
<th>Communication (patient specific)</th>
<th>Region A</th>
<th>Region B</th>
<th>Region C</th>
<th>Region D</th>
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<tbody>
<tr>
<td>Palliative care specific protocols shared between service providers</td>
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<tr>
<td>Mechanism for patient-specific communication between service providers including multidisciplinary rounds</td>
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<tr>
<td>Sharing of patient’s record among palliative care providers</td>
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<tr>
<td>Information sharing within our organization addressed client needs</td>
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</tr>
<tr>
<td>Information sharing between organizations addressed client needs</td>
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**Figure 5.** System coordination indicators.
In contrast, Region B service providers communicated through weekly, multidisciplinary rounds or meetings. In Region D, service providers communicated through the in-home chart, telephone, reports, and cancer center case rounds.

The presence of designated roles and responsibilities in the provision of palliative care services found in Regions B and D was not evident in Regions A and C. Similarly, acute care hospital beds were more regularly used for palliative care patients in regions A and C, often because of a lack of designated palliative care beds or residential hospice beds.

Most respondents stated that determining the palliative care patient’s desired place of death was routine practice; however, only in Region C did respondents indicate with any certainty that patients were given the option to die at home. A barrier to the provision of support for home death that was common to Regions B and C was a family’s ability to manage the patient without sufficient supportive resources. In Region A the main barrier was perceived to be the lack of willing participation by family physicians, while in Region D, it was the discomfort of some providers with the notion of a home death.

Finally, we found differences in the provision of death certification in the home. In Region D there was common mention of expected death planning. In contrast, in Region C, emergency medical services (EMSs) (i.e. ambulance and police services) were more frequently used to transport patients who died in the home to the emergency room for death certification without registering a visit. This was accomplished by the attending physician certifying the deceased in the ambulance outside the emergency room. In the other regions, the most common scenario was for a doctor to pronounce and certify the death, although sometimes the family had to wait until the following morning. In Region B, for those within the limited catchment of the demonstration end-of-life program, most often a palliative care physician would pronounce and certify death.

Document review

The document reviews offered little useful data to inform the state of palliative care delivery in each region besides providing some indication of physical resources, such as hospitals and residential hospices. No reports containing a region-wide palliative care needs assessment were found for any of the regions close to or prior to the study years of reference. Typically, reports with some relevance to palliative care focused on future planning directions for long-term care or were based on aggregate province-wide data or analyses of either small areas or sub-populations within the region. In collecting the reports from each region, it was found that more research activity relating to end-of-life care had occurred in Regions B and D, compared to Regions A and C.

Discussion

The organization and delivery of palliative care programs and services continues to challenge health systems internationally. A single approach or model is not applicable to all settings given the heterogeneity of system structures, and other local contextual factors, such as geographic diversity or rurality. Jurisdictions have attempted to apply the overarching principles of quality provision to achieve best possible care for patients with advanced illness, most often based on expert opinion. This study was designed to explore whether structures and processes could be clearly identified that are associated with more favorable acute care utilization rates.

Our findings further the understanding of the palliative care system and program configuration variables contributing to regional variation in population-based health utilization outcomes. Using population outcomes from regional administrative data available in Ontario, the study team was able to select large health regions with higher or lower utilization profiles. Through a rigorous, literature-informed conceptual approach, we were able to create a detailed description of each region with respect to processes of care using tools that were empirically supported to examine the system variables that might contribute to regional variation. The visual array analysis of patterns clearly delineated a number of discriminating features between regions of higher and lower acute care use at the end of life. This insight into probable antecedents demonstrates a proof of principle to further inform the development of models of palliative care and their evaluation at the regional level.

The comparative analysis revealed a large number of common elements between regions that reflected the overall state of the health system during the time of inquiry. These shared characteristics included insufficient financial resources, inequitable access to relevant services for end-of-life patients, and little capacity-building activity. There was no overall health system palliative care planning in the province during the time of inquiry. Nonetheless, we were able to identify six key features that were present in regions with better population-level performance (i.e. higher home death rate and less ED use). These were:

- palliative care specific planning and coordination;
- specified resources, including an advanced practice nursing presence;
- 24/7 palliative care team access;
use of a patient common chart to facilitate provider communication;
standardized patient assessments;
designated roles for the provision of palliative care services.

The literature on evaluating palliative care programs is limited, particularly in terms of comprehensive studies comparing delivery features between multiple systems. One such study examined six regional palliative care networks in the Netherlands by surveying network providers with respect to structure, process, and outcome level measures. Points of inquiry regarding ‘processes’ included organization and management, cooperation, and external relationships, while those for ‘outcomes’ included the extent of shared objectives and perceptions, the demand for care, the quality of cooperation, the improvement of care services, achieved agreements, expertise, and funding. Important success factors for the networks identified were mutually productive contacts, regular funding, and the collective development of care activities. The process-level factors of this study were not quantified, nor linked directly to patient-level outcomes to suggest associations.

A number of systematic reviews and meta-analyses have examined the benefits of interdisciplinary, palliative homecare programs. Most programs that have been studied incorporate a number of the key features we found in our study and facilitate comprehensive professional support in the home for palliative care patients and their family caregivers. These interventions are often centered on a care coordinator (often a nurse), who provides around-the-clock in-home professional support appears to be one of the critical factors to avoiding unnecessary transfer to acute care facilities for patients at the end of life. Community-based palliative care teams have been found to contribute to fewer hospitalizations, ED visits, and hospital deaths, as well as other improved patient outcomes. A review by Gomes and Higginson, examining environmental factors within a palliative care system, found that greater use and intensity of home care services (as well as a rural location and a lack of in-patient beds) was associated with a greater probability of a home death. More recent studies, one a randomized controlled trial (RCT) and the other based on hospital administrative data, found that palliative care teams in the community were associated with significant reductions in hospital readmission costs, compared to usual standard care. The RCT also found that patients receiving this team care had significantly fewer ED visits (35% less), were more likely to die at home (75% in intervention compared to 51% in control), and expressed greater satisfaction with service. Finally, a newly published trial reported that lung cancer patients assigned to early palliative care in an outpatient setting not only had a better quality of life and fewer depressive symptoms, but also longer median survival than did patients assigned to standard care. Our research builds upon all these findings by illuminating these process and structure features that are likely essential components of well-functioning community-based palliative care programs.

The limitations of this study need to be noted. The retrospective accounts provided by key informants may have been subject to recall bias, which would have impacted our findings. Respondents were asked to provide dates corresponding to any system initiatives or implementations they mentioned that may have affected the presence or absence of the feature being discussed, for example, common patient information forms. This helped ensure that key informants kept their perceptions to the study’s time of reference and provided chronological information to assist the research team to corroborate these statements through the document review. A further issue is that case studies involving large geographic areas may lack the detail to capture local pockets of relative excellence or deficiency in palliative care provision. Our findings represent the general state of palliative care in each region not the range of potential diversity in each.

An additional limitation of this study is that we did not elicit the perceptions of referring professionals (oncologists, family physicians, informal caregivers, or patients relative to the palliative care characteristics measured. Future replication of our methodology should strive to include these important perspectives. A recent study by Alonso-Babarro et al. in Italy followed a cohort of patients receiving community-based palliative care to examine factors associated with a home death. They found that three factors strongly predicted for home death after discharge: patients’ preferred place of death, caregiver’s preferred location of death, and caregiver’s perceived social support. These findings further enhance the understanding of our derived association between system competency for community palliative care provision and acute care utilization.

With the recent proliferation of palliative care networks internationally, systematic examination of these interventions is essential to determine their effectiveness and inform further organization of services. The results of our study contribute to understanding the important elements in palliative care program development at the regional level. We plan to further test our framework to evaluate structure and process elements of palliative care systems that are currently being established in the Ontario health care system.
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Conflict of interest statement
None declared.

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References

**Appendix A: semi-structured interview data points**

1. Palliative care system structure.
2. Overall mechanism/forum for palliative care system planning/management.
3. Palliative care specified resources.
4. Service provider designated roles/responsibilities in relation to palliative care.
5. Palliative care specific policies shared between agencies.
7. How this needs assessment information was used.
8. Mechanism to ensure the coordination of palliative care services.
9. Palliative care specific protocols shared between service providers.
10. Mechanism for patient-specific communication between service providers.
11. How patients identified as needing palliative care.
12. How community’s capacity to provide palliative care monitored.
13. Mechanism for monitoring shared throughout the community (yes/no).
14. Resources in/adequate to provide needed palliative care services.
15. Areas where resources inadequate to provide needed services.
16. Role of acute care hospital non-ALC (Alternate Level of Care) beds relative to palliative care services.
17. Home care services always available to patients when needed.
18. Limitations of the home care services provided to cancer patients in the palliative stages.
19. Home care services responsive to all of the patients’ needs (yes/no).
20. Limitations of the home care services to respond to the patient’s needs.
21. Nursing shift care always available to patients as needed (yes/no).
22. Specific eligibility criteria necessary for patients to meet before they could receive services (yes/no).
23. Description of eligibility criteria for patients to meet before they could receive services.
24. Patients/health care providers able to access specialized palliative care services on 24/7 basis (yes/no).
25. Nature of specialized palliative care coverage in community.
26. Key barriers to accessing community-based palliative care services (yes/no).
(27) Description of key barriers to accessing community based services.
(28) Circumstances where a palliative care patient may have used the hospital emergency room.
(29) Reason for a palliative care patient would be admitted to hospital through the emergency room.
(30) Estimate of the proportion of cancer-related deaths that would have occurred in the home.
(31) Home death consistently offered to palliative care patients (yes/no).
(32) Barriers to the provision of support for home death.
(33) How pronouncement of death was handled in the home.
(34) How certification of death in the home was handled.
(35) Percentage of palliative care patients with access to coverage (%).
(36) Major strengths in community for the provision of palliative care services.
(37) Major weaknesses in community’s ability to provide palliative care services.

Appendix B: survey data points

(1) Institutions that provided in-patient palliative care.
(2) Number of ‘palliative care’ physicians in region.
(3) Physicians made house calls.
(4) Physician provided palliative care on 24/7 basis.
(5) Number of advanced practice nurses.
(6) Nursing agencies who had a team of specialized palliative care nurses.
(7) Dedicated palliative care consult teams at specified sites.
(8) Allied health palliative care specialist present.
(9) Available 24/7.
(10) Designated palliative care case managers.
(11) Patients whose palliative care needs were assessed (%).
(12) Significant (longer than one week) waiting lists for palliative care services.

Palliative care system perception questions
(1 = Agree strongly to 4 = Disagree strongly)

a. All support services that were needed, were available.
b. Resources were adequate to provide the needed services.
c. Services were responsive to individual diversity.
d. Services were accessible to those who need them.
e. Services were available to clients when they need them.
f. Resources were allocated on the basis of client need.
g. Sufficient outreach and information was provided.
h. Information sharing within our organization addressed client needs.
i. Information sharing between organizations addressed client needs.
j. Overall, I was satisfied with the service delivery system in my community.