Workforce Planning Survey of Specialist Palliative Care Program Nurses in 2018 in Nova Scotia, Canada

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Beth Tupala led in the design and administration of the survey, and analysis of findings. Grace Johnston provided input on the design and analysis, and led in drafting this report. In his role as Principal Investigator of the operations research project, Majid Taghavi provided input on the design, analysis, and drafting of this report. All authors are responsible for the content of this report.

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On March 21st, 2018, the Research Ethics Board (REB) of the Nova Scotia Health Authority (NSHA) informed us that the survey did not require REB review.

We followed practices expected for routine NSHA operations.

The NSHA is not responsible for any errors in this document, and the NSHA may interpret the survey findings in a manner that is different from that of the authors.

We thank the specialist palliative care program nurses from across Nova Scotia for their assistance by completing the survey. Thank you also to the Nova Scotia Health Research Foundation for Development and Innovation funding for development of an operations research model to forecast staffing needs.

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Executive Summary

This report describes the methods and findings from a survey in late April 2018 of specialist palliative care program nurses across Nova Scotia, Canada. The survey was designed to provide parameters for an operations research (OR) model to estimate the specialist palliative care program staffing needed across the province over the next twenty years (2019-2038). Open-ended questions were also incorporated to inform the model development process.

While OR is widely valued by management in a wide range of industries, its use to date in health care resource planning has been limited. A high-level review of the literature indicated no prior use of this method for palliative care human resource planning. Thus, workforce planning using OR methods applied to palliative care is cutting-edge research.

The survey was distributed to the 52 specialist palliative care program nurses across the province. The overall response rate was 69%. The nurses reported that 60% of their time was related to direct patient care, 20% to other educational and administrative tasks, and 20% to travel. They identified the tasks that they carried out related to direct patient care as well as the other tasks that were part of their workload. They reported that the factors that were most likely to affect the amount of time they needed to spend with a patient were the severity of symptoms, type of disease (cancer, organ failure, frailty), and education needed by the patient and family. On average, the nurses reported that, compared to cancer, persons dying of organ failure required a similar amount of time but persons with dementia or frailty typically required less of their time. However, the range of responses was wide especially for organ failure. Additional very insightful comments were provided by the nurses.

In time, more extensive and further validated information will hopefully become available to inform and adjust the mathematical model to assist in more extensive and fully informed development of a model of palliative care. In the meantime, this survey and its findings provide a more solid, multi-factorial base for discussion and decision making than has been available to date.

Background

Various reports highlight a lack of and inequities in access to palliative care across Canada (Canadian Cancer Society (2016); Canadian Hospice Palliative Care Association (2015); Covenant Health (2016)). In addition, our population is ageing (Statistics Canada (2019)) and this means that an increasing number of adults will need palliative care at the end of their lives. Among those who die each year, more than 90% have a life-limiting chronic disease that would benefit from advance care planning prior to death (Canadian Hospice Palliative Care Association (2019)) and the majority would benefit from palliative support (Murtagh et al. (2014); Rosenwax et al. (2005)).

The distribution of palliative care services in Canada has largely been a result of local initiative and lobbying (Williams et al. (2010)) resulting in variation by geographic area (Health Canada (2018); Nova Scotia Department of Health and Wellness (2014)). The benchmarks that have been used to date for palliative care workforce planning have been simplistic; typically, they do not incorporate the wide range of relevant factors (Raine (2017)). Therefore, the development of a method to improve human resource planning for palliative care was critically important.

Thus, our research question was: how do we incorporate the plethora of factors that are pertinent to optimally plan for the number and distribution of specialist palliative care program personnel needed for a geographic area now and in the future? In many industries, operations research (OR) has been used to solve human resource problems such as this (Grunow et al. (2004); Lavieri & Puterman (2009); Lavieri et al. (2008); Vanhoucke & Maenhout (2007)). While OR is increasingly being used in health care, from our review of the literature (Raine (2017)), OR had not been used as yet to plan for specialist palliative care personnel.

To develop our OR model, we needed a clearer understanding of how specialist palliative care program nurses across the province spend their time and the factors that determine the time that they need for patient care. Other OR parameters were available from the Nova Scotia Health Authority (NSHA) and other sources.

From a high-level scan of the literature, no previous studies were identified that delineated the tasks of specialist community-based palliative care nurses, their time allocation, or changes that they predict in their role in the future. Therefore, we designed a survey to solicit this otherwise unavailable but necessary information from the specialist palliative care nurses themselves.

With Development and Innovation grant funding from the Nova Scotia Health Research Foundation, we developed an OR model to generate a set of solutions for our workforce planning problem. Our OR model incorporates a diverse but limited set of relevant factors into a mathematical formula to predict the optimal number of specialist community-based palliative care program nurses, physicians, and social workers needed over the next 20 years across Nova Scotia (NS). The OR Method details are reported elsewhere (Taghavi & Johnston (2020)).

The goal of the OR modeling project was to plan for adequate quality community-based specialist palliative care program staffing for all persons living with a life-limiting advancing chronic conditions. Therefore, this Workforce Planning Survey excludes palliative care for hospital in-patients because:

• hospital inpatient unit staff are not part of community-based palliative care programs for which the Director of Palliative Care Integration has planning responsibility,

- inpatient unit nurse staffing is typically based on hospital-wide resource planning and funding,
- not all hospitals across the province have specifically designated in-patient palliative care beds,
- some patients receive palliative care as an inpatient but not in a designated palliative care bed,
- some hospital staff providing inpatient care to patients needing palliative support may not have specialist palliative care training, and
- it is challenging to define the timeline and boundaries of inpatient palliative care nursing.

Since nurses working in palliative care units in hospitals and out-patient clinics were not included in this survey, the palliative care nurses based at the children's hospital were not included.

To help ensure that timely palliative care is available early, the disease trajectories of those at the end of life must be taken into account. In the past, palliative care was mainly for persons dying of cancer. Increasingly, palliative care is advised for persons with organ failure (e.g., congestive heart failure, chronic obstructive pulmonary disease, renal failure) and frailty (Murray et al. (2005)). The timing of functional decline varies by disease trajectory from six months for cancer, to 2-5 years for organ failure, and up to ten years for frailty (Lunney et al. (2003)).

Purpose of this Report

This report describes the methods and findings from a survey of NS specialist palliative care program nurses that was designed to provide parameters for an OR model (Taghavi, Johnston, et al. (2018)). By making this report publicly available, we invite others to refine and adapt our methods to compute and validate comparable parameter values. Thereby, in time, a more fully informed OR solution can be generated.

This factual report provides and accepts the survey methods and findings without providing extensive critique. A paper that is more grounded in the academic literature is being prepared for submission for publication.

Survey Objectives

The primary objective of the nurses' survey was to obtain an estimate of H_{ti}^D which is a parameter (i.e., set of quantitative values) that is needed to solve the OR model (Taghavi, Johnston, et al. (2018)). H is the direct patient care time (in hours) by specialist palliative care program nurses per patient. D is the set of disease groups considered. t is the set of future years for which the human resource plan is being projected which in this case is 2019-2038. t is the set of 14 geographic networks in Nova Scotia.

A secondary objective of this survey of nurses was to obtain insight into the factors that the nurses believed to affect their use of time now and are likely to affect their time in the future. For this, openended questions were included.

Methods

Setting

In NS, over 9,000 persons die each year (Statistics Canada (2019)). The NS Integrated Palliative Care Strategy (Nova Scotia Department of Health and Wellness (2014)) said that palliative care was already being provided by specialist palliative care programs across the province but also could be provided by other trained personnel from primary care, disease-specific medical specialties, and other forms of care. A letter of support for this study was received from the Nova Scotia Health Authority (NHSA) (Cochrane (2017)); it stated that our OR project provided a "structured scientific approach .. [that] aligns with our provincial model of care ... [and] is of interest". The caveat was added that support for the OR project findings "does not commit the NSHA to implement the findings".

Questionnaire development and pilot testing

To develop the survey questionnaire, the study lead [BT] referred to literature on the principles of questionnaire design for nursing research (Rattray & Jones (2007)). Palliative care practitioners, health system managers, and an expert in questionnaire design were consulted. The questionnaire was pilot tested with a representative sample of nurses (1 urban, 1 rural, 1 hospital-based, 1 community-based). Using this input, the online, anonymous questionnaire was developed and refined.

Survey distribution process

The community-based palliative care program managers from the nine palliative care teams across the province were contacted individually to explain the nurses' survey and the OR project. In late April 2018, BT sent them 1) an explanation of the project, 2) a link to an online, anonymous survey, and 3) a request to distribute the questionnaire to the 52 community-based specialist palliative care program nurses in NS. The deadline for survey responses was provided. There was one follow-up reminder.

Items in the survey and their deployment

The nurses were only asked questions that were relevant to the OR model development. They were asked:

- "In which NS management zone do you work?" The options for answering were: Central, Northern, Eastern, and Western. This question was asked to ensure that there was representation from all geographic zones. To ensure confidentiality, the findings are not reported by the zone.
- "What is your estimate of the number of your patients who have died in an average year?" This was asked since we needed to calculate the number of direct patient care hours per patient. From other data sources, we knew the total number of hours that nurses were expected to work each year. We had also obtained the annual time for vacation and sick time and statutory holidays. Total hours per patient was defined as the total hours a nurse works per year (excluding statutory holidays, vacation and sick time) divided by the average number of patients for whom they provided care, that die each year.
- "Do you work full-time as a specialist palliative care nurse? If you are not full-time, how many hours a week do you work as a specialist palliative care nurse?" This information was used to prorate the hours in the preceding calculation.

For the OR model, the parameter that we needed was the direct care time per patient (H), not the total nurse time working. Therefore, we asked the nurses what percentage of their time was spent on direct patient care versus other tasks (i.e., travel and administrative duties).

We wanted to be clear about what we defined as *direct patient care* and to try to ensure that all the nurses had the same or a similar understanding when completing the questionnaire.

There was no available province-wide standard definition of what constituted direct patient care by a community-based specialist palliative care program nurse. Therefore, BT referred to literature on key attributes of the community palliative care specialist nurse role (Cameron & Johnston (2015)) and the role of palliative care nurses (Mulvihill et al. (2010)). BT reviewed a provincial environmental scan that she carried out in 2016. She also incorporated her first-hand experiential knowledge from working as a palliative care nurse. From this, BT, in consultation with GJ and MT in relation to the purpose of the OR modelling project, agreed upon a list of tasks to include in the survey (Table 1). In the survey, the nurses were asked if they carried out each of the items listed and were provided the opportunity to add any tasks that they felt were not adequately covered in the list. We included advance care planning and support of the family as well as the patient, but we did not include bereavement care after the death.

Before the nurses reported the percentage of time that they believed that they spent on direct patient care, we also wanted them to have a clear understanding of what was not included as direct patient care. Therefore, in the survey, we provided a list of specific administration, meeting, education and other tasks (Table 2) that we defined as not being directly related to the care of their own patients. In the survey, we provided the opportunity for the nurses to list other non-direct patient care tasks.

We knew that travel time varied across the province and so we wanted to separate travel time from other non-direct patient care time. When we asked the nurses the percentage of time they spent traveling, we included both the time traveling to and from patient visits as well as to other meetings or for other tasks.

After providing these clarifications, the questionnaire included the following questions:

- "In your role as a specialist palliative care nurse, are you responsible for doing the following tasks?" This question was asked for direct patent care, tasks that were not direct patient care, and travel. Each of the three sets of tasks was followed by:
- "Please add any tasks directly related to patient care that you think are missing." Thereafter, the nurses were asked:
- "Based on all of your responses above, on average, in a year, what percent of your time would you estimate is spent on the following?" i.e., direct care, travel, and other tasks not directly related to patient care.
- The nurses were told that the three percentages that they reported should add up to 100%.

The next two questions were optional. They were:

- "Given your previous responses, please think about tasks that could be carried out by other healthcare providers (such as palliative care physicians, social workers, home care, care coordinators, primary care, etc.) as opposed to tasks that you think should be done by specialist palliative care nurses" and
- "Do you have any comments regarding the previous question?".

Thereafter, the nurses were asked to:

"Please indicate if you think the following are factors that affect the amount of time you spend
with a particular patient and/or family, from when they are first known to your program until
death/discharge." Table 3 lists the factors provided for their consideration. This list was limited to

- factors for which we knew we could get estimates from existing population-based data for incorporation in an OR model. The nurses were then asked to
- "Please add any factors that you think are missing" since we wanted to know if there were
 important factors for which rigorous data development would need be needed before
 incorporation in the OR model.

For the OR project, we wanted to incorporate one factor, but only one factor, that the nurses thought might influence the total time they needed to care for a patient. A requirement for the factor selected was that we needed to be able to obtain a population-based quantification of this factor by the number of persons affected each year across the province from an extant data source. Death counts by the main cause of death and demographics could be obtained from Vital Statistics death certificate data. Fassbender et al. (2006) had developed a taxonomy that used the main cause of death from Vital Statistics death records to group into three disease groups that benefit from palliative care: cancer, organ failure, and frailty. Etkind et al. (2017) developed a taxonomy that separated out dementia. Therefore, we selected cause of death (defined as cancer, organ failure, frailty, and dementia) as the factor to incorporate into the OR model. This led to the next section of the questionnaire which was challenging to develop and for the nurses to answer.

Since historically, cancer was the dominant disease group for which palliative care was provided, we asked the nurses to use cancer as their base for comparison in terms of whether more or less of their time was needed for persons dying primarily of organ failure, frailty, and dementia. We then asked the nurses to estimate approximately how much more or less time than they thought would be needed; to answer this, we provided them with a table of options.

The following open-ended questions were then asked to guide further refinement of our model and to identify next steps and limitations:

- Do you anticipate any changes in your role/tasks as a specialist palliative care nurse over the next 20 years?
- What changes do you anticipate?
- Do you have any other comments or questions that you would like to share with us?
- Are there more factors we should consider in planning for the future specialist palliative care?

Analysis and reporting

BT used Excel to generate descriptive statistics to summarize the questionnaire responses. BT grouped responses to open-ended questions when more than one nurse reported the same or a very similar answer. Thereby, responses are reported in total so that full access to the study findings are made available.

Results

Among the 52 nurses who were sent the questionnaire, 36 (69%) responded and initially 27 (52%) answered all the questions. Among the 27 who completed the entire survey, 14 (52%) worked full time, and 13 (48%) worked part time in the community as a specialist palliative care program nurse. The respondents were from all four geographic zones in the province.

Among the 27 who complete the entire survey, the full-time nurses saw an average of 110 new patients a year. The part-time nurses saw an average of 44 new patients a year.

Tasks and time for direct patient care, tasks not directly related to patient care, and travel

The great majority of patent care (Table 1) and non-patient care tasks (Tables 2) listed in the survey were carried out by all nurses completing the survey. However, there was variation by geographic zone on the time that specialist palliative care program nurses spend on case management and physical nursing care. Less than half of the nurses said that they provided physical nursing care and only about three quarters said they were doing case management (Table 1, italicized rows).

The additional patient care (Table 1) and non-patient care (Table 2) tasks that the nurses listed were grouped into themes. They provide further insight into the role played by specialist palliative care program nurses.

Table 1: Number (percentage) of nurses doing specified tasks directly related to patient care

To also	Number			
Tasks	(Percent)			
Comprehensive assessment	28 (97%)			
Physical nursing care	13 (45%)			
Referrals to/enrolment in other programs	28 (97%)			
Psycho-social-spiritual support	28 (97%)			
Patient and/or family education	28 (97%)			
Caregiver Support	28 (97%)			
Supportive phone calls to patients and/or families	28 (97%)			
Advance Care Planning/Planning for Death discussions	28 (97%)			
Documentation of visits and phone calls	28 (97%)			
Guidance (formal or informal) to other care providers regarding your patient	28 (97%)			
Care coordination	27 (93%)			
Case management	22 (76%)			
Sending orders/faxing forms, etc.	27 (93%)			
E-mail or other communications regarding patients and/or families	27 (93%)			
Additional patient care tasks added by the nurses surveyed				
Assistance with bringing supplies/equipment to a home, disposing of fluids after a home procedure, etc.	3			
CADD Pumps: setting up, supplies, troubleshooting, delivery	2			
Triaging referrals, preparing charts for visit	1			
Communications with the rest of the team, copy my documentation for others	1			
Assessment of financial needs	1			
Facilitating discharge from acute care facility	1			
Enlisting primary care to follow suggestions of palliative care	1			
On-going problem solving for unexpected needs	1			

Tasks	Frequency	
Preparing, delivering palliative care education to formal care providers or public	27 (93%)	
1:1 informal palliative care teaching of family physicians, other nursing staff, etc.	27 (93%)	
Attending team meetings and other meetings	28 (97%)	
Attending education events or completing annual required education	28 (97%)	
E-mail, phone and other communication unrelated to specific patients	27 (93%)	
Guidance (formal or informal) to other care providers re other patients (not yours)	27 (93%)	
Additional non-patient care tasks added by the nurses surveyed		
Participating in policy development or patient/family materials/guides	2	
Liaison or membership with local palliative care society, preparing for hosting meetings, etc.	2	
Organize yearly memorial service for families	2	
Sitting on various provincial and program committees; planning hospice	2	
Mentorship and preceptorship	1	

The nurses reported that 60% of their time was related to direct patient care, 20% to other educational and administrative tasks and 20% to travel when medians were computed (Figure 1). The corresponding mean values are 59%, 23%, and 17%. Variations were observed in the percentage of time they spent on: tasks related to a specific patient's or family's care (20-90%), tasks not related to a specific patient or family (7.5-45%), and travel (0-40%).

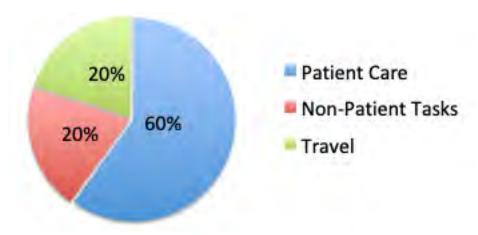


Figure 1: Median time that nurses spend on patient care, non-patient care tasks, and travel

Time for tasks that should only be carried out by a specialist palliative care nurse

The nurses reported an average (mean) time of 59% (median of 63%) spent on tasks that should only be done by specialist palliative care program nurses. They reported that 25% could be done by another health care professional such as palliative care physicians, social workers, home care, care coordinators, and

primary care who had appropriate training. A further 16% (median 10%) of tasks could be done by clerical or administrative staff. There was considerable variation in the perception of how much of their work could be performed by other health care providers (10-45% across the 24 respondents) and clerical staff (5-40% across the 25 respondents).

Additional comments that the nurses provided were:

- "Social work and spiritual care dedicated to our teams would be of great benefit" (2 people),
- "Large amount of time spent on clerical work increased clerical support it would allow me to see a few more patients/week",
- "Often doing tasks that are not directly palliative care, such as assisting other patients to the washroom",
- "With proper education and support, Primary Care would be able to do more of the tasks that are currently deemed as requiring palliative care specialists",
- "A lot of my time is spent on the emotional feeling of patients patients might feel comfortable talking only with me because I established that relationship with them", and
- "Often working as case manager because there is no one else to fill the role. I get called with questions that are better suited for other providers, but they know that I will follow up in a more timely manner".

These open-ended responses from the nurses helped provide some understanding of reasons for variations in work being carried out by specialist palliative care program nurses and served to validate that a proportion of the time they were spending on tasks could (and maybe should) be done by others.

Factors that influence the direct patient care time needed

When the nurses were provided with a list of factors that might influence the total time they needed to care for a patient, the three factors that were most frequently reported as affecting patient care time were the nature or severity of symptoms, disease (frailty, organ failure, dementia, cancer), and education of patients and/or family members (Table 3). The two next most frequently reported were that the patient does not have a family physician and that there was no family member, friend, or neighbor available to help.

Table 3: Number (percentage) of nurses reporting factors affecting the nursing time required

Factor	Number (percent)
	+
Nature or severity of symptoms	28 (100%)
Disease (frailty, organ failure, dementia, cancer)	25 (89%)
Education of patient and/or family members	25 (89%)
Patient does not have a family physician	24 (86%)
No family member, friend, or neighbor to help	24 (86%)
Distance from a palliative care team location	19 (68%)
Age of patient	19 (68%)
Patient is a resident in long-term care facility	14 (50%)
Income of patient/family	12 (43%)

In response to an open-ended question, the nurses listed the following other factors that they felt also affected the amount of palliative care needed. Multiple reports of the same factor are noted in brackets.

- Inadequate home care supports/availability of VON/involvement of homecare (3),
- Family/primary care provider anxiety/emotions; family dynamics (3),
- Level of involvement of the family physician (2),
- Lack of other care providers who should fulfill the role (2),
- Alcohol or drug misuse (patient and/or primary caregiver),
- Family/primary care provider underlying illness/poor health,
- Type of disease: ALS would be a disease that would affect the amount of time spent,
- Lack of resources,
- Their grief experiences,
- Their previous experience with palliative care,
- Early integration of palliative care, and
- Willingness of patient/family to allow involvement of other providers i.e. social workers.

Thus, there are a lot of factors that likely affect the time that a nurse needs to care for a patient.

The total nursing time needed compared to that for a cancer patient

The nurses were asked, compared to a patient with cancer, on average, do you think you spend more or less time overall with other patient populations. Approximately half (48%) of the nurses thought that persons with organ failure took more of their time than persons with cancer, and the other half (52%) thought less time (Table 4). In contrast, only about a quarter of the nurses thought that persons with frailty or dementia took more time (25% and 20% respectively).

Table 4: Time spent in direct care provision per patient, compared to a patient with cancer

	More	Less
Organ Failure	12 (48%)	13 (52%)
Frailty	6 (25%)	18 (75%)
Dementia	5 (20%)	20 (80%)

The nurses were then asked to provide a quantitative estimate of how much more or less time, using 100* for cancer as the base for comparison (Figure 2). For those that thought less time was needed, a bit less time was the most common response. In contrast, among those that thought more time was needed, some thought that a person with organ failure could take double the amount of time that a person with cancer would take. The blue bars in Figure 2 below show a wide distribution in responses from the nurses on how much of their time would be needed for a person with organ failure.

^{*} The value 100 has no intrinsic meaning in this study. It is simply a quantitative foundation for making comparisons, much the way we use percentages which have 100% as a base and from that we can get an impression of what is meant by other values such as 125% and 80%.

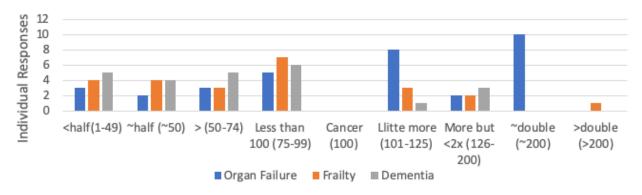


Figure 2: Nursing time needed compared to Cancer, using 100 as a base for comparison

Changes that the nurses expect in future

Most nurses (96%) reported that they expected changes in the future in the role of the specialist palliative care program nurse. The changes they expected were:

- "More time spent as a specialist nurse on the more complex cases" (9),
- "Increasing caseloads; increasing demand" (7),
- "More time spent teaching and mentoring other health care professionals" (6),
- "Primary teams starting palliative care approach earlier and referring to palliative care specialists later on" (3),
- "Increased education requirements for specialist nurses" (4),
- "Increase in patient acuity" (2),
- "Increase in computerization (negative/neutral)" (2) "positive" (1),
- "Hope for more SW [social work] resources" (2),
- "Closer dialogue with the medical oncologists; family doctors" (2),
- "Increased percentage of dementia patients in our palliative care population",
- "New cancer treatments might improve patient outcomes, so possibly a decrease in % of cancer on our caseloads",
- "Future studies on MAiD [Medical Aid in Dying] might influence bereavement services",
- "More case management",
- "Specialist nurses being trained for both hospital and community roles",
- "More capacity building, but more resources are required to allow us to do this", and
- "VON [Victorian Order of Nurses] shortages will increase our involvement in care (inappropriately)".

The nurses were given the opportunity to provide additional comments. The comments included a need for more: palliative care program physicians and nurses working in the community (3), and nurse practitioners, dedicated bereavement coordinators, and multidisciplinary teams (2). They also reported a need to build capacity and mentoring within palliative care teams to plan for the aging and retirements in palliative care providers (3), more research provincially (2), educating other specialty nurses and all frontline staff (2), and administrative support, specifically for a doctor.

They said that because the workload was heavy and staffing levels were low, they see patients much later in the trajectory of their illness than is ideal. They reported a need to move toward electronic charting and blackberry/cell phone scanners and faxing ability, as well as to overcome obstacles to using telehealth

with patients in more remote areas. They reported the need for time for education and program development, and time every few months to debrief losses if staff wished. In areas with clinics, there was a need for a nurse-run clinic mixed with a physician/nurse clinic to manage the anticipated increase in patient numbers.

There was a need to balance provincial work and standards with the acknowledgment of local variations. The long-term care sector needed to have its own specialist palliative care nurses. There was a need for more continuing care assistants and Victorian Order of Nurses staff if they were to be the frontline providers for the bulk of the care. The current structure did not provide the level of support that the clients required, e.g., one nurse reported that they only had a half time specialist palliative care physician to cover three counties.

These two respondent quotes provide an overarching perspective of the views of the nurses are:

- As a palliative nurse in the community there are days, I am very overwhelmed with responsibilities of the job. There are many new referrals (approx. 27 last month and approx. 27 deaths). As a result, the caseload numbers stay the same but the work that is required is a lot. I would like to spend more time on symptom management, support, education and coordination of care but I feel I am only going from one crisis to another. I would like to have the time to be proactive in these areas.
- There needs to be a standard ratio of population to palliative care resources, including social work. There needs to be equality across the province in palliative care services.

Discussion

This report describes the methods and findings from a survey of community-based specialist palliative care program nurses. The survey was designed specifically to provide parameters for an operations research (OR) model. The quantitative values from the survey were used as parameters in the OR model. Posters summarize the method and findings of this report (Taghavi,Tupala,et al. (2018)) as well as the OR model and findings (Taghavi,Johnston,et al. (2018)).

This is not a comprehensive description of the role of the palliative care nurse. Furthermore, in the literature, there are ambiguities in the definition of the role of the specialist palliative care nurse, for example as reflected in the terms "specialized palliative care nurse" versus "clinical nurse specialist". In practice, the responsibilities and time available for the nurses are not consistent across the province. Their tasks may differ between urban and rural settings, and in accord with the availability of other services. Regardless, we used the averages computed to solve the OR model as a 'proof of concept' and thereby enable discussion and a base for future refinement.

A strength in using OR is that a wide range of parameters can be incorporated at once into a single model. However, accurate empirical data needs to be available for each parameter incorporated. Our goal was to demonstrate that OR modelling could incorporate a much wider range of factors than had previously been used for estimating palliative care staff needs. However, we realize that many additional relevant factors were not included in the survey of nurses and thus in our OR model prototype. We felt that a longer questionnaire would be an additional burden on the nurses without major benefit in the primary goal of demonstrating the value of using OR.

For example, in our OR model, we wanted to demonstrate that we could take into account the type of patient when projecting the palliative care staffing required in the future. We only needed to choose one factor to carry out this demonstration. Table 3 and the responses from the nurses reveal additional relevant factors that could be incorporated as parameters in a future OR model.

Furthermore, to solve the OR model, various assumptions were made when accurate empirical data were not available. Two of these assumptions were:

- There was no difference in direct care nursing time needed per patient across the geographic networks or overtime, and
- All palliative care program nurses operated in the same way in terms of time needed to complete
 their role in providing quality patient palliative care. This means that we assumed that the time
 the nurses needed did not vary by their number of years of experience, prior education, being
 part versus full time, or other factors.

Making assumptions such as these means that the solution to the OR model is not as robust as stakeholders might wish. However, the assumptions do not undermine what has otherwise been learned from the survey. The survey provides a solid base upon which to build.

In time, better information will hopefully become available to inform and adjust the mathematical model and to assist with the development of a more fully informed model of palliative care for our province and for adaptation and use elsewhere. In the meantime, this survey and its findings provide a method and data directly from the specialist palliative care program nurses themselves that to date had not been available.

Conclusion

To address the unmet need for palliative care, workforce planning is essential. This nurse survey generated data used in an OR model to estimate the number of specialist palliative care program nurses needed across Nova Scotia over the next 20 years. Furthermore, the study findings provide much-needed insight into the role that community-based specialist palliative care program nurses are carrying out in Nova Scotia as well as the many challenges and potential system adaptations that they expect that they are likely to face in the years ahead.

References

Cameron, D., & Johnston, B. (2015). Development of a questionnaire to measure the key attributes of the community palliative care specialist nurse role. *International Journal of Palliative Nursing*, 21(2), 87–95. https://doi.org/10.12968/ijpn.2015.21.2.87

Canadian Cancer Society. (2016). Right to Care: Palliative care for all Canadians, by Canadian Cancer Society.

Canadian Hospice Palliative Care Association. (2015). The way forward national framework: A roadmap for an integrated palliative approach to care.

Canadian Hospice Palliative Care Association. (2019). Speak up.

Cochrane, T. (2017). Letter dated March 21st from the Vice President, Integrated Health

- Services Program, Primary Health Care and Population Health, Nova Scotia Health Authority, Halifax, NS.
- Covenant Health. (2016). Palliative care matters: How Canada's health system needs to change. Consensus statement of the palliative care matters lay panel.
- Etkind, S. N., Bone, A. E., Gomes, B., Lovell, N., Evans, C. J., Higginson, I. J., & Murtagh, F. E. M. (2017). How many people will need palliative care in 2040? Past trends, future projections and implications for services. *BMC Medicine*, *15*(1), 102. https://doi.org/10.1186/s12916-017-0860-2
- Fassbender, K., Smythe, J. G., Carson, M., Finegan, B. A., & Boothe, P. M. (2006). *Costs and utilization of health care services at end of life in Alberta 1999-2002*.
- Grunow, M., Günther, H.-O., & Yang, G. (2004). Development of a decision support model for scheduling clinical studies and assigning medical personnel. *Health Care Management Science*, 7(4), 305–17. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/15717815
- Health Canada. (2018). Framework on Palliative Care in Canada.
- Lavieri, M. S., & Puterman, M. L. (2009). Optimizing nursing human resource planning in British Columbia. *Health Care Management Science*, *12*(2), 119–128. https://doi.org/10.1007/s10729-008-9097-0
- Lavieri, M. S., Regan, S., Puterman, M. L., & Ratner, P. A. (2008). Using operations research to plan the British Columbia registered nurses' workforce. *Healthcare Policy = Politiques de Sante*, 4(2), e117-35. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/19377361
- Lunney, J. R., Lynn, J., Foley, D. J., Lipson, S., & Guralnik, J. M. (2003). Patterns of functional decline at the end of life. *JAMA*, *289*(18), 2387. https://doi.org/10.1001/jama.289.18.2387
- Mulvihill, C., Harrington, A., & Robertson, A. (2010, April). A literature review of the role of the specialist palliative care community nurse. *International Journal of Palliative Nursing*. MA Healthcare Ltd. https://doi.org/10.12968/ijpn.2010.16.4.47781
- Murray, S. A., Kendall, M., Boyd, K., & Sheikh, A. (2005). Illness trajectories and palliative care. *BMJ*, 330(7498), 1007–1011. https://doi.org/10.1136/BMJ.330.7498.1007
- Murtagh, F. E., Bausewein, C., Verne, J., Groeneveld, E. I., Kaloki, Y. E., & Higginson, I. J. (2014). How many people need palliative care? A study developing and comparing methods for population-based estimates. *Palliative Medicine*, *28*(1), 49–58. https://doi.org/10.1177/0269216313489367
- Nova Scotia Department of Health and Wellness. (2014). *Integrated palliative care: Planning for action in Nova Scotia*.
- Raine, E. (2017). Existing Literature in Human Resource Planning in Palliative Care. Presentation at the "Planning for the number of palliative care specialists in Nova Scotia" meeting on December 14, 2017 in the School of Health Administration, Dalhousie University.
- Rattray, J., & Jones, M. C. (2007). Essential elements of questionnaire design and development. *Journal of Clinical Nursing*, *16*(2), 234–243. https://doi.org/10.1111/j.1365-2702.2006.01573.x
- Rosenwax, L., McNamara, B., Blackmore, A., & Holman, C. (2005). Estimating the size of a

- potential palliative care population. *Palliative Medicine*, *19*(7), 556–562. https://doi.org/10.1191/0269216305pm1067oa
- Statistics Canada. (2019). *Table 17-10-0008-01 Estimates of the components of demographic growth, annual.*
- Taghavi, M., & Johnston, G. (2020). *Palliative Care Workforce Planning using Operations Research: Methods used in Nova Scotia Project*.
- Taghavi, M., Johnston, G., Urquhart, R., Henderson, D., Tschupruk, C., & Tupala, B. (2018). Planning for the number and distribution of specialist palliative care personnel in Nova Scotia. International Congress on Palliative Care. Montreal.
- Taghavi, M., Tupala, B., & Johnston, G. (2018). Collecting palliative care nursing data for use in workforce planning. In *International Congress on Palliative Care*. Montreal.
- Vanhoucke, M., & Maenhout, B. (2007). NSPLib: A nurse scheduling problem library: a tool to evaluate (meta-)heuristic procedures. *Operational Research for Health Policy: Making Better Decisions*, 151–165. Retrieved from https://biblio.ugent.be/publication/666107
- Williams, A. M., Crooks, V. A., Whitfield, K., Kelley, M.-L., Richards, J.-L., DeMiglio, L., & Dykeman, S. (2010). Tracking the evolution of hospice palliative care in Canada: A comparative case study analysis of seven provinces. *BMC Health Services Research*, 10(1), 147. https://doi.org/10.1186/1472-6963-10-147