

Palliative care as an emerging role for respiratory health professionals: Findings from a cross-sectional, exploratory Canadian survey

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Introduction: Respiratory Health Professionals (RHPs) with specialty training in the management of asthma and COPD, often care for patients with advanced respiratory disease, who have less access to palliative care than patients with similar disease burden. The aims of this study were to: (i) explore the current and desired roles of RHPs in terms of palliative care and (ii) examine barriers to discussions with patients about palliative care.

Methods: An online survey addressing the aims of this study was developed and pilot tested. The survey was distributed nationally using the database of the Lung Association's RESPTREC respiratory educator training program. Descriptive statistics were performed.

Results: A total of 123 completed surveys were returned, with respiratory therapists comprising the largest group of respondents. The majority indicated that end-of-life care was less than optimal for patients with advanced respiratory illnesses and agreed that palliative care should be a role of RHPs. Patient- and family-related barriers to having end-of-life discussions included: difficulty accepting prognosis, limitations and complications, and lack of capacity. For providers, the most important barriers were: lack of training, uncertainty about prognosis, and lack of time. The health care system barriers of concern were increasing demand for palliative care services and limited accessibility of palliative care for those with advanced respiratory diseases and difficulties in accurate prognostication for these conditions.

Discussion: Incorporating a more defined role in palliative care was generally seen as a desirable evolution of the RHP role. A number of strategies to mitigate identified barriers to discussions with the patient are described. Better alignment of the services required with the needs of patients with advanced respiratory disease can be addressed in a number of ways.

Conclusions: As RHP roles continue to evolve, consideration should be given to the ways in which RHPs can contribute to improving the quality of care for patients with advanced respiratory disease. Building collaborations with RHPs, palliative care, and other existing health programs can ensure high quality of care. Creating and taking advantage of learning opportunities to build skills and comfort in using a palliative approach will benefit respiratory patients.

Key Words: Palliative care; End-of-life care; advanced respiratory disease; COPD; advanced care planning; respiratory health professionals; certified respiratory educators; Medical Assistance in Dying

INTRODUCTION

Chronic respiratory diseases are currently the fifth leading cause of death in Canada [1]. The Conference Board of Canada [2] forecasts that the prevalence of chronic lung diseases will increase by 32% (1.6 million cases) between 2010 and 2030, primarily reflecting the growing number of older adults living with Chronic Obstructive Pulmonary Disease (COPD) or lung cancer. Deaths due to idiopathic pulmonary fibrosis are steadily increasing worldwide [3], while pulmonary arterial hypertension [4] and cystic fibrosis [5] are well-recognized as life-limiting illnesses. Symptoms commonly experienced in advanced respiratory diseases include: dyspnea, cachexia, hemoptysis, fatigue, cough, psychosocial discomfort, and pain [6].

Around the world, demographic and disease trends are transforming the landscape of health care needs. In 2017, over 275,000 Canadians died [7], a number that will continue to increase as the population grows and ages. It is estimated that between 62% and 89% of all those who die would benefit from palliative care [8]. Of people who died in Canadian hospitals, a 2018 report by the Canadian Institute of Health Information (CIHI) suggested that 94% may have benefited from palliative care services [9], although these services are not universally accessible.

Palliative care is defined as “the active holistic care of individuals across all ages with serious health-related suffering due to severe illness, and especially those near the end of life” [10]. Palliative care can be provided alongside disease-modifying treatments and supports patients to live as fully as possible until death. Palliative care includes “prevention, early identification, comprehensive assessment and management of physical issues...psychological distress, spiritual distress and social needs” [10]. Access to palliative care services has been associated with the following improved outcomes: greater patient satisfaction with care [11, 12], decreased symptom burden [13, 14], fewer emergency department visits [9, 15, 16], reduced hospital admissions [15], reduced lengths of stay [15], 30-day re-admissions [16, 17], reduced likelihood of admission to the intensive care unit [9], less likelihood of avoidable hospital transfers from long-term care [9], and a greater likelihood of dying at home [9]. These potential outcome improvements warrant closer examination of the ways in which palliative care might contribute to care of patients with advanced respiratory diseases.

Although the need for palliative care for patients with advanced respiratory disease is increasingly recognized [18–20], these services are often conspicuously inaccessible for this population [21, 22]. Noncancer deaths are responsible for more than two-thirds of all deaths in Canada [23, 24],

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yet cancer patients were found to be three times more likely to receive palliative care, either in hospital or at home, than Canadians with other diagnoses [9]. While symptom burden, care trajectories, and health status can be similar, the quality and access to palliative care of those with advanced Chronic Obstructive Pulmonary Disease (COPD) has been reported to be relatively poor compared to those with lung cancer [18, 25]. Patients with COPD receive more aggressive treatment at the end of life and less palliative care than those with lung cancer, even though they report similar preferences for palliative care [26]. In a study of place of death in 14 countries, Cohen et al. [27] found that those dying from COPD were less likely to die at home or in a palliative care setting and more likely to die in a hospital or nursing home than patients dying from lung cancer. The palliative care needs of patients with Interstitial Lung Disease are strikingly similar to those in malignant disease [28], but palliative care services for this group are only now being developed.

Three types of barriers to accessing palliative care for patients with advanced respiratory diseases have been identified. These include barriers relating to: (i) health care providers, (ii) health care systems, and (iii) patients themselves. Providers have reported insufficient time and (or) skills to discuss palliative care, as well as concerns that such discussions might diminish hope [29, 30]. Implicit bias on the part of providers against patients with smoking-related respiratory diseases may contribute to decreased accessibility of palliative care, especially when patients continue to smoke [31]. The increasing demand for palliative care services within health care systems [32, 33] limits accessibility for those with advanced respiratory diseases, as do the difficulties in accurate prognostication for these conditions [34, 35]. The stigma and guilt associated with smoking may cause some patients to delay seeking diagnosis and treatment. Patients may also fear abandonment by their usual health care team if they access palliative care services [6, 29] or they may hold negative attitudes towards palliative care [35, 36].

Despite these challenges, new models integrating palliative care and chronic disease management for patients with advanced respiratory disease have reported positive outcomes. Examples of novel services include: patient-centred medical homes [37], breathlessness services that provide early access to palliative care [38, 39], and an Advanced Lung Disease Service [40]. Within Canada, the INSPIRED COPD Outreach Program™ [41] and the subsequent pan-Canadian care collaborative [42] reported rapid changes to work practices, cultural change, and skills sets at a relatively low cost. Common to these new programs is an interdisciplinary approach.

Across Canada, Medical Assistance in Dying (MAiD) became law through Bill C-14 in 2016, providing another end-of-life care option for eligible Canadian adults with a “grievous and irremediable medical condition” who make a voluntary request and can provide informed consent [43]. Nurse practitioners and physicians can legally administer MAiD services in Canada [43]. Up until 31 October 2018, 6749 Canadians have opted for MAiD, with circulatory/respiratory disease noted as the underlying medical circumstance in between 11% and 17% of cases [44].

Respiratory health professionals (RHPs) such as respiratory therapists, nurses, pharmacists, and rehabilitation therapists often receive specialty training in asthma and COPD chronic disease management to become Certified Respiratory Educators (CREs). CREs educate clients about their asthma or COPD and motivate them to self-manage their disease. CREs are trained how to assess patient knowledge, desires, and acceptance of prognosis [45], although these supports are often provided by professionals without CRE specialty training. Many patients, however, may not have access to this education and support [46, 47]. RHPs with chronic disease management knowledge clearly make significant contributions to the care of patients with advanced respiratory diseases, although their involvement in providing palliative care in Canada has not been clearly articulated.

The aim of this cross-sectional study was to explore the current and desired roles of RHPs in the palliative care of patients with advanced disease and to examine barriers to having discussions with patients related to palliative care faced by these providers. The findings of this initial study were intended to provide direction for further research into the roles of RHPs in palliative care.

METHODS

Approval to conduct the study was granted by the University of Saskatchewan Behavioural Research Ethics Board (BEH# 18-147). A search for publications related to RHPs' perceptions of and involvement in palliative care did not identify existing questionnaires that could address the aims of this study. The authors developed a 27-item survey suitable for online administration based on key concepts identified from the literature review. Fourteen additional items elicited salient demographic and professional characteristics. The survey was pilot tested with three RHPs for clarity and content. Minor revisions were made to the survey. The online survey was hosted through Voxco and consent was presumed if the individual completed the survey. Because we were interested in gaining a wide spectrum of perspectives on desired roles, individuals who did not currently provide palliative care for respiratory patients were eligible to participate.

Definitions of palliative care were provided at the beginning of the survey, along with the following three questions reported in the literature [8] that could help participants consider whether patients with advanced respiratory disease could be considered to be close to the end of life: (i) “Would you be surprised if your patient died within the next year?”, (ii) “Does your patient show general indicators of decline?” (e.g., repeated, unplanned hospital admissions; presence of significant co-morbidities), and (iii) “Does your patient have at least two respiratory-specific indicators of advanced disease?” (e.g., eligible for long-term oxygen, Medical Research Council (MRC) grade 4 or 5).

The survey was comprised of four sections and included: (i) Likert-type items that measured level of agreement with a range of statements salient to current and preferred practice and roles in palliative care of patients with advanced respiratory disease and (ii) fixed-choice items eliciting preferences regarding care, barriers to enacting palliative care roles, and the characteristics of current educator practices. Demographic items addressed professional, training, and geographic attributes.

Surveys were electronically distributed in English to 3204 RHPs from across Canada on the RESPTREC mailing list in September, 2018, for a period of 30 days. The RESPTREC mailing list consists of all health professionals who have taken a minimum of one respiratory educator course from this program since 2001. RTs comprise 39% of the list, while nurses, pharmacists, and others (therapists and dieticians) make up 36%, 13%, and 12%, respectively. Consent to participate was implied by completion of the survey and a full description of the intent of the survey was provided. A reminder e-mail was sent out after 1 week. Responses were anonymous and returned to the social sciences research laboratory.

Descriptive and univariate analyses were conducted based on 123 completed surveys using SPSS v. 25 in consultation with a statistician. Multilevel responses to the survey items were dichotomized for clarity of interpretation. Frequencies were computed for all variables and presented as observed/totals and percentages. Associations were examined using cross-tabulation, χ^2 , or Kruskal-Wallis ANOVA statistics as appropriate. The significance level was set a priori at 0.05. Surveys missing in excess of 50% of item responses were not included in the analyses. While there were relatively few missing responses to the survey, average imputation was used, whereby the mean for the sample for that item was used.

RESULTS

Three hundred and five individuals opened the survey and 123 RHPs completed the entire survey, for an in-scope response rate of 40.3% and an overall response rate of 3.8%. Respiratory therapists (RTs) accounted for 87 (70.7%) of respondents, while nurses ($n = 19$; 15.4%), pharmacists ($n = 5$; 4.1%), physiotherapists ($n = 4$; 3.3%), and other health professionals ($n = 8$; 6.5%) accounted for the remainder. Given the uneven distribution of professional designations, this category was collapsed into RTs ($n = 87$) and other respiratory health professionals ($n = 36$) for purposes of statistical analyses.

Table 1 provides an overview of demographic, personal, and employment characteristics of respondents. Chi-square and Kruskal-Wallis ANOVA analyses were performed as appropriate and no significant differences could be detected between RTs and other RHPs on any variable.

TABLE 1
Demographic, personal, and employment characteristics of respondents (n = 123).

Characteristics	No. (%) Respiratory Therapists, (n = 87)	Other respiratory professionals (n = 36)	Overall n = 123	p
Gender				
Female	73 (83.9)	35 (97.2)	108 (87.8)	NA
Male	14 (16.1)	1 (2.8)	15 (12.2)	NA
Geographic location				
Western Canada	39 (44.8)	19 (52.8)	58 (50.1)	0.61
Ontario	30 (34.5)	12 (28.6)	42 (34.1)	0.61
Atlantic Canada	18 (20.7)	5 (13.9)	23 (18.7)	0.61
Distance to urban centre of >250,000				
Located in urban centre	22 (25.3)	13 (36.1)	35 (28.5)	0.35
<250 km	42 (48.3)	17 (47.2)	59 (48.0)	0.35
≥250 km	23 (26.4)	6 (16.7)	29 (23.6)	0.35
Has personal experience with serious illness or death of someone close	70 (80.5)	15 (79.0)	98 (79.7)	0.46
Self-rated importance of spirituality				
Somewhat important or important	48 (56.5)	24 (66.7)	72 (58.5)	0.40
Neutral	18 (21.2)	4 (11.1)	22 (17.8)	0.40
Somewhat unimportant or unimportant	19 (22.4)	8 (22.2)	27 (21.9)	0.40
Years of professional experience				
≤10 years	13 (14.9)	8 (22.2)	21 (17.1)	0.41
11–25 years	47 (54.0)	15 (41.7)	62 (50.4)	0.41
≥25 years	27 (31.0)	13 (36.1)	40 (32.5)	0.41
Is a Certified Respiratory Educator	76 (88.4)	16 (84.2)	105 (86.1)	0.26
Has attended workshops or professional education on palliative care	32 (36.8)	18 (51.4)	50 (40.7)	0.26
Practice setting				
Asthma/COPD/ Cough Clinic	21 (24.1)	3 (8.3)	24 (19.5)	NA
Primary health care	11 (12.6)	10 (27.8)	21 (17.1)	NA
Acute care	17 (19.5)	4 (11.1)	21 (17.1)	NA
Home Care	7 (8.0)	3 (8.3)	10 (8.1)	NA
Community Care	6 (6.9)	2 (5.6)	8 (6.5)	NA
Other (including: mixed acute care and community, pharmacies, private practice)	25 (28.7)	14 (38.9)	39 (30.1)	NA
Primary patient populations seen in practice (multiple allowed)				
Chronic cough	86 (98.9)	36 (100)	122 (99.2)	NA
COPD	86 (98.9)	34 (94.4)	120 (97.6)	NA
Interstitial Lung Disease	58 (66.7)	18 (50.0)	76 (61.8)	NA
Asthma	42 (48.3)	21 (58.3)	63 (52.3)	NA
Lung Cancer	33 (37.9)	15 (41.7)	48 (39.0)	NA
Pulmonary Hypertension	21 (24.1)	6 (16.7)	27 (22.0)	NA
Lung Transplant	14 (16.1)	3 (8.3)	17 (13.8)	NA
Cystic Fibrosis	8 (9.2)	1 (2.8)	9 (6.5)	NA

Note: NA, not available as cell counts of <5 precluded statistical analyses.

Respondents were distributed across Western Canada, Ontario, and Atlantic Canada, with close to half reporting residence outside of, but within 250 kilometres, of an urban centre with a population of 250,000 people or more. The majority (82.9%) were seasoned health care professionals with 11 or more years of professional experience in practice settings that included respiratory disease such as COPD (98.9%) and Interstitial Lung Diseases (66.7%). Approximately 41% had attended workshops or professional education related to palliative care.

Respondents' current participation in palliative and end-of-life care is reported in Table 2. Again, no significant differences between the groups were identified and are not reported in the table. Close to three-quarters of respondents reported deaths from respiratory disease on their caseloads. Significant variability was noted in the frequency of having end-of-life discussions with patients. Only 17.1% of respondents reported that more than half of the patients for whom they cared had written advance care plans, although most respondents (65.0%) indicated they were comfortable discussing advance care plans. The absence of an advance care plan was noted as an important barrier to having end-of-life discussions with their patients by 60.2% of respondents. The majority (88.6%) did not discuss MAiD with their patients.

The most important patient- and family-related barriers reported by respondents to having end-of-life discussions involved: patient (88.6%) and family (91.7%) difficulty accepting prognosis, patient lack of capacity (91.9%), lack of agreement amongst family members regarding palliative care (91.1%), and patient difficulty accepting limitations and

complications (87.8%). In terms of provider barriers, three-quarters of respondents noted uncertainty about prognosis (76.4%) and lack of training to have discussions (74.0%). Lack of time (71.5%) was the next most frequently reported barrier, followed by disagreement among team members (61.5%). A significant difference between RTs and RHPs was noted in terms of the desire to maintain hope as a barrier to end-of-life discussions, with fewer RTs indicating that this was a barrier.

To examine variations in current palliative care services across jurisdictions, these analyses are reported by region in Table 3. No significant differences were identified between regions using Kruskal-Wallis ANOVA testing. The majority (61.0%) of respondents disagreed with the statement "Patients with advanced respiratory illness received optimal end-of-life care." One-third of respondents (32.5%) indicated the transition process between acute care, the community, and palliative care was smooth. Over half of respondents (55.3%) agreed that palliative care was currently a role of respiratory educators. While there was near-unanimous agreement (95.1%) that patients had a negative perception of the term palliative care, fewer (58.5%) agreed that their colleagues had a negative perception of this term. Overall, 48% of respondents reported that there were dedicated supportive or palliative care services available to patients with advanced respiratory disease in their practices and a similar proportion believed that these services met most or all patient needs. Half of the respondents (51.1%) currently worked collaboratively with palliative care services.

Table 4 displays respondent's perspectives on incorporating further focus on palliative care into the RHP role. Almost all (93.5%) agreed that

TABLE 2

Current respiratory health professional participation in palliative and end-of-life care

	Respiratory Therapists (n = 87)	Other Respiratory Professionals (n = 36)	Overall n = 123	p
Frequency of deaths/month from respiratory disease on respondent caseload				
0	6 (6.9)	2 (5.6)	8 (6.5)	NA
≤5	50 (57.5)	22 (61.1)	72 (58.5)	NA
>5	16 (18.4)	3 (8.3)	19 (15.4)	NA
Unsure	15 (17.2)	9 (25.0)	24 (19.5)	NA
Frequency of providing end-of-life care to respiratory patients				
Once a month or more	24 (27.6)	6 (16.7)	30 (24.4)	NA
Several times a year	29 (33.3)	11 (30.6)	40 (32.5)	NA
Once a year	13 (14.9)	3 (8.3)	16 (13.0)	NA
Never	21 (24.1)	16 (44.0)	37 (30.1)	NA
Frequency of having end-of-life discussions with respiratory patients				
Always/often	17 (19.5)	9 (25.0)	26 (21.1)	0.75
Sometimes	36 (41.4)	15 (41.7)	51 (41.5)	0.75
Rarely/never/not in my scope of practice	34 (27.6)	12 (33.3)	46 (37.4)	0.75
Proportion of respiratory patients with Advance Care Plan (estimated)				
<25%	35 (40.2)	16 (44.4)	51 (41.5)	NA
26%–50%	11 (12.6)	5 (13.9)	16 (13.0)	NA
≥50%	17 (19.5)	4 (11.1)	21 (17.1)	NA
Unsure	24 (27.6)	11 (30.6)	35 (28.5)	NA
Level of comfort discussing Advance Care Plans				
Comfortable	56 (64.4)	24 (66.7)	80 (65.0)	NA
Neutral	12 (13.8)	3 (8.3)	15 (12.2)	NA
Uncomfortable	19 (21.8)	9 (25.0)	28 (22.8)	NA
Discuss MAiD with patients				
Yes	7 (8.0)	7 (19.4)	14 (11.4)	0.70
No	80 (92.0)	29 (80.6)	109 (88.6)	0.70
Important patient and family barriers to end-of-life discussions				
Patient difficulty accepting prognosis	75 (86.2)	34 (94.4)	109 (88.6)	0.23
Patient difficulty accepting limitations and complications	78 (89.7)	30 (83.3)	108 (87.8)	0.40
Family member difficulty accepting prognosis	78 (89.7)	34 (94.4)	112 (91.9)	0.49
Patient lack of capacity	78 (89.7)	35 (97.2)	113 (91.9)	0.16
Lack of agreement amongst family members regarding palliative care	77 (88.5)	35 (97.2)	112 (91.1)	0.10
Language barrier	67 (77.0)	31 (86.1)	98 (79.7)	0.25
No advance care plan	48 (55.2)	26 (72.2)	74 (60.2)	0.08
Important provider barriers to end-of-life discussions				
Uncertainty about prognosis	65 (74.7)	29 (80.6)	94 (76.4)	0.49
Lack of training to have discussion	68 (78.2)	23 (63.9)	91 (74.0)	0.10
Desire to maintain hope	34 (39.1)	22 (61.1)	56 (45.5)	NA
Not part of my role/scope of practice	25 (28.7)	14 (38.9)	39 (31.7)	0.48
Lack of time	60 (68.2)	28 (77.8)	88 (71.5)	0.32
Disagreement among team members	51 (58.6)	24 (66.7)	75 (61.0)	0.41
Own belief system	17 (19.5)	10 (27.8)	27 (22.0)	0.32

Note: NA, not available as cell counts of <5 precluded statistical analyses. MAiD, medical assistance in dying.

palliative care and management of advanced symptoms should be an integral role of the RE and that chronic disease management and palliative care can be offered at the same time (91.1%). Most respondents (66.7%) indicated that the best time to offer palliative care was at the diagnosis of advanced illness (MRC 4). Within this group of respondents, there was a high degree of interest in further training in palliative care. Because of cell sizes of <5 for each of the variables, only descriptives are reported.

DISCUSSION

As key members of the health care team, RHPs have significant influence over the quality of care and an emerging opportunity to influence quality exists in the area of care in advanced respiratory disease. Incorporating a more defined role in palliative care was seen by most respondents to this survey as a desirable evolution in professional responsibility, particularly given that deaths of respiratory patients were not uncommon on caseloads, and there was variability in access to palliative care services across Canada. Variability in RHP practice with respect to discussing preferences for end-of-life care was noted, as was the use of advance care plans. The most important patient- and family-related barriers to having end-of-life discussions included difficulty

accepting prognosis, limitations, and complications, as well as patient lack of capacity. For providers, the most important barriers to having these discussions were lack of training, uncertainty about prognosis, and lack of time. Important opportunities to improve the quality of care at the end of life exist in closer collaboration between RHP and formal palliative services and participation in providing support patient transitions between settings. Chronic disease management and palliative care were not viewed by respondents as mutually exclusive foci of care, but could be integrated to better address the needs of patients.

Our findings support imperatives to incorporate a palliative approach into the care of patients with advanced respiratory disease, which have been framed from the perspectives of both justice and redressing health care disparities [30]. Applying the principle of justice means that appropriate palliative care support should be available to all patients with similar needs, irrespective of diagnosis [30, 32]. While the burden of advanced respiratory disease has been demonstrated to equal or surpass that of cancer [39, 40], patients with chronic lung disease have less access to and receive fewer palliative care services [48, 49]. One strategy to address these disparities could involve engaging RHPs in a palliative care role.

One important component of incorporating palliative care principles into the practice of RHPs involves engaging in discussions related to

TABLE 3
Perspectives on current respiratory palliative care services by region

	Western Canada (n = 58)	Ontario (n = 42)	Atlantic Canada (n = 23)	Overall	p
Patients with advanced respiratory illness receive optimal end-of-life care					
Disagree	38 (65.5)	22 (52.4)	15 (65.2)	75 (61.0)	NA
Neutral	0	0	0	0	NA
Agree	20 (34.5)	20 (47.6)	8 (34.8)	48 (39.0)	NA
Transition process is smooth between acute care, community care and palliative care					
Disagree	36 (62.1)	19 (45.2)	9 (39.1)	64 (52.0)	NA
Neutral	7 (12.1)	8 (19.0)	4 (17.4)	19 (15.4)	NA
Agree	15 (25.9)	15 (35.7)	10 (43.5)	40 (32.5)	NA
Palliative care is currently a role of RHPs					
Disagree	22 (37.9)	19 (45.2)	7 (30.4)	48 (39.0)	NA
Neutral	4 (6.9)	1 (2.4)	2 (8.7)	7 (5.7)	NA
Agree	32 (55.2)	22 (32.4)	14 (60.9)	68 (55.3)	NA
Patients have a negative perception of the term palliative care					
Disagree	2 (3.4)	3 (2.4)	1 (4.3)	6 (4.9)	NA
Agree	56 (96.6)	39 (92.9)	22 (95.7)	117 (95.1)	NA
Colleagues have a negative perception of the term palliative care					
Disagree	25 (43.1)	16 (38.1)	10 (43.5)	51 (41.5)	0.86
Agree	33 (56.9)	26 (61.9)	13 (56.5)	72 (58.5)	0.86
Dedicated supportive or palliative care services for patients with advanced respiratory disease					
Yes	25 (43.1)	20 (47.6)	14 (60.9)	59 (48.0)	NA
No	19 (32.8)	9 (21.4)	7 (30.4)	35 (28.5)	NA
Unsure	14 (24.1)	13 (44.8)	2 (8.7)	29 (23.6)	NA
Extent to which existing palliative care services meet patient needs					
No services or does not meet needs at all	7 (12.2)	6 (14.3)	2 (8.7)	15 (12.2)	NA
Meets needs to some extent	15 (25.9)	8 (19.0)	3 (13.0)	26 (21.1)	NA
Meets most or all needs	26 (44.8)	16 (38.1)	15 (65.2)	57 (46.3)	NA
Unsure	10 (17.2)	12 (28.6)	3 (13.0)	25 (20.3)	NA
RE works collaboratively with PC services					
Yes	32 (55.2)	19 (45.2)	12 (52.2)	63 (51.2)	0.62
No	26 (44.8)	23 (54.8)	11 (47.8)	60 (48.8)	0.62

Note: NA, not available as cell counts of <5 precluded statistical analyses. RHP, Respiratory Health Professionals; RE, Respiratory Educator; PC, Palliative Care.

TABLE 4
Perspectives on incorporating further palliative care focus into the respiratory health professional (RHP) role

	Respiratory Therapists (n = 87)	Other respiratory professionals (n = 36)	Overall (n = 123)
Palliative care and management of serious symptoms should be an integral role of RHPs			
Disagree	3 (3.4)	2 (5.6)	5 (4.1)
Neutral	1 (1.1)	2 (5.6)	3 (2.4)
Agree	83 (95.4)	32 (88.8)	115 (93.5)
Chronic disease management and palliative care can be offered to a patient at the same time			
Disagree	6 (6.9)	3 (8.3)	9 (7.3)
Neutral	2 (2.3)	0	2 (1.6)
Agree	79 (90.8)	33 (91.7)	112 (91.1)
When is the best time to offer palliative care services for respiratory patients?			
At the time of diagnosis	4 (4.6)	3 (8.3)	7 (5.7)
At diagnosis of moderate illness (MRC 3)	9 (10.3)	4 (30.8)	13 (10.6)
At diagnosis of advanced illness (MRC 4)	58 (66.7)	12 (63.2)	82 (66.7)
In the last 6–12 months of life	9 (10.3)	1 (2.8)	10 (8.1)
In the last 3–6 months of life	6 (4.9)	4 (11.1)	10 (8.1)
In the last month of life	1 (1.1)	0	1 (0.8)
Interest in palliative care training			
Yes	79 (91.9)	30 (83.3)	109 (89.3)
Unsure	7 (8.1)	5 (13.9)	1 (0.8)
No	0	1 (2.8)	12 (9.8)

future care and care preferences with patients with advanced respiratory disease. Patient and family difficulties in accepting prognosis and limitations were found to be an important barrier by respondents to having these discussions. This challenge may be due, in part, to the insufficient disease-specific knowledge and health literacy on the part of patients and family members, including the usual course of the illness. Several studies

have reported inadequate knowledge was common with both respiratory patients and family members [50, 51]. In COPD, a higher level of knowledge was associated with better adaptation to the illness [50]. Given that patient and family education is a primary role of most RHPs, additional focus on assessing level of knowledge about the disease may help to mitigate the difficulties that have been reported in accepting prognosis.

Uncertainty about prognosis was also reported as an important barrier to engaging in end-of-life discussions. While prognostic uncertainty remains a challenge in advanced respiratory disease [52], a focus on the actual needs of the individual patient, rather than their prognosis, can allow for the incorporation of palliative care principles such as management of distressing symptoms at any time in their care trajectory.

Lack of capacity also served as a barrier to engaging in end-of-life discussions for many respondents. Growing evidence suggests an association between cognitive impairment and COPD [5, 53, 54], which has been attributed to the hypoxemia seen in some patients with COPD affecting the synthesis of neurotransmitters such as acetylcholine [53]. A systematic review [55] found considerable impairment of both memory and attention in patients with COPD, which may be worse in patients with advanced disease. While lack of capacity can be a clear barrier to engaging in end-of-life discussions with patients with advanced respiratory disease, RHPs who understand that cognitive impairment may be an outcome may serve their patients well by having advance care planning discussions earlier, rather than later, in the course of care. A minority of respondents to this survey, however, were able to report that 50% of more of the patients on their caseloads with advanced respiratory disease had advance care plans.

Maddocks et al. [56] have called for new models of care integrating respiratory medicine, primary care, and rehabilitation services, which could be further enhanced by integrating palliative care principles [41]. The successful integration of chronic disease management and palliative care within a seamless model of respiratory care has been previously reported [35-40], although widespread adoption of these models will require major reforms in policy, resource allocation, and practice. Four central challenges to advancing palliative care reforms in general have been noted: (i) limited knowledge about palliative care in health care, including lack of training; (ii) cultural beliefs about palliative care; (iii) payment/reimbursement for palliative care services; and (iv) limited public awareness and understanding of palliative care [57]. To transition to new models of care for patients with advanced respiratory disease, these same issues will require concerted and ongoing advocacy on the part of health care providers, patients and families, and charitable organizations.

Limitations

This cross-sectional survey was designed to explore the current and desired roles of RHPs in palliative care to inform the feasibility of future research in this area. While our survey findings included the responses of 123 RHPs representing most regions of Canada (with the exception of Quebec) and reflect diverse population densities, the findings of this survey are not generalizable to the entire population of Canadian RHPs. The RESPTREC database was selected because it potentially covered a wide cross-section of Canadian respiratory health professionals, with the exception of those in Quebec. This database covered an 18-year span of time and likely contained contacts no longer practicing in the area of respiratory health, limiting our ability to construct a contained sampling frame. Soliciting respondents from provincial or national professional licensing bodies may have provided a more reliable sampling frame. Response bias was likely in that RHPs with a pre-existing interest in palliative care chose to complete the survey. The use of nonparametric analysis was appropriate for the relatively small sample size, but no statistically significant differences could be detected between either professional groups or geographic regions. Given the absence of validated surveys addressing the research question, survey items had to be developed by the authors to capture data most salient to the objectives.

Implications for clinical practice

For RHPs who care for patients with advanced respiratory disease, care should be taken to identify needs that can be best served using a palliative care approach. Because this holistic approach encompasses attention to psychological distress, spiritual distress, and social needs, as well as physical issues, some respiratory services may not feel adequately resourced to respond effectively to the range of needs identified. Documentation of patient needs can build the evidentiary base typically

required by funders to reallocate resources. Building collaborations with other existing services to address these needs once they have been identified can help enormously to ensure a high quality of care. Creating and taking advantage of learning opportunities to build skills and comfort in using a palliative approach will also be of benefit to RHPs and the patients they serve. Learning from the best practices of other RHPs, across Canada and globally, who care for patients with advanced respiratory disease has significant potential to improve care.

CONCLUSIONS

The quality of care for patients with advanced respiratory disease can be enhanced by integrating principles of palliative care into chronic disease management [55]. Because many RHPs already work in interdisciplinary teams, they can take on leadership roles in promoting the need for palliative care on their services. RHPs can help to address the gaps in care identified in this exploratory survey, including limited access to palliative care and difficult transitions through collaboration, training, and research.

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Contributors

DG and JP contributed to the conception or design of the work, as well as the acquisition, analysis, or interpretation of the data. DG and JP were involved in drafting and commenting on the paper and have approved the final version.

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Competing interests

All authors have completed the ICMJE uniform disclosure form at www.icmje.org/coi_disclosure.pdf and declare: no financial relationships with any organizations that might have an interest in the submitted work in the previous 3 years; no other relationships or activities that could appear to have influenced the submitted work.

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