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Title: Prevalence and risk factors of breathlessness across Canada: A national retrospective cohort study in home care and nursing home populations

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Abstract

Background: Breathlessness is a symptom associated with poor clinical outcomes and prognosis. Little is known about its long-term trends and associations with social factors including decline in social activities and caregiver distress.

Objectives: To describe factors associated with the prevalence of clinician-reported breathlessness across Canada among cohorts receiving home care or nursing home care.

Methods: A retrospective observational cohort study of cross-sectional intake assessment data from Canadian interRAI Home Care and Nursing Home datasets. In each dataset, we examined covariates associated with the presence of clinician-reported breathlessness using multivariate regression.

Results: Between 2007-2018, we identified 1,317,117 and 469,709 individuals from the home care and nursing home datasets, respectively. Over two-thirds were aged >75 and over 60% were women. Breathlessness was present at intake in 26.0% of the home care and 8.2% of the nursing home cohorts. Between 2007 to 2018, prevalence of breathlessness increased by 10% for the home care cohort, while remaining relatively constant in nursing homes. Covariates associated with increased odds of having clinician-reported breathlessness at intake in both cohorts were: moderate-severe impairment with activities of daily living, being male, older age, high pain scores, signs of depression, and decline in social activities. In the home care cohort, the presence of breathlessness was associated with a greater odds of caregiver distress (OR=1.19, 95% CI: 1.18-1.20).

Conclusion: The prevalence of clinician-reported breathlessness is higher in home care than nursing home populations, the former having risen by 10% over the decade. Prevalence of breathlessness is associated with decline in social activities and caregiver distress. Enhanced supports may be required to meet increasing patient need in the community.

Key message: This article describes the prevalence of clinician-reported breathlessness between 2007-2018 across Canadian cohorts receiving home care (26.0%) or nursing home care (8.2%) at intake assessment. Increased odds of breathlessness at intake was associated with: functional impairment, males, older age, high pain scores, signs of depression, decline in social activities, and caregiver distress.

Introduction

Breathlessness is a symptom that limits all aspects of life and is associated with poor clinical outcomes, such as more hospitalizations and emergency department visits, and poorer prognosis. It is estimated to vary in the general population from 9% to 59% with a higher prevalence in women and older adults.[1-3] The most common causes are cardiorespiratory conditions, such as chronic obstructive lung disease and chronic heart failure, and cancer.[1] Breathlessness that persists despite available effective interventions to manage the underlying cause is defined as Chronic Breathlessness Syndrome.[4] It is especially prevalent towards the end of life,[1,5] with research showing 54% of people reported breathlessness in the their last week of life.[6] Prior research has shown that breathlessness is associated with declining physical function, anxiety and depression.[1,7,8] Research has examined breathlessness in hospital, community-dwelling older adults, end-of-life and hospice populations,[1,6,7,9]

However there are gaps in knowledge about how factors such as decline in social activities (e.g., reduced participation in preferred activities) are associated with breathlessness and the impact on caregivers.[10,11] In prior research of a home care cohort of cancer patients in the last 6 months of life, we examined the trajectory of psychosocial symptoms, including caregiver distress and decline in social activities, but excluding breathlessness.[12] To our knowledge, there are no published comparisons between breathlessness at intake among people with any disease requiring home-based care in the community or nursing home care. Understanding breathlessness is important in these two populations, given the associations between chronic breathlessness and poor clinical outcomes, such as more frequent hospitalizations and emergency department visits, and poorer prognosis.[7] Potentially most importantly, we lack national data examining changes in the prevalence of breathlessness over the years.

A unique opportunity exists in Canada to address these knowledge gaps. Across most provinces, standardized comprehensive assessments derived from the same family of interRAI assessment tools have been used in both home care and nursing home populations for over 10 years. The interRAI suite of tools is equivalent to the Minimum Data Set (MDS) in the United States[13,14] and has been validated in other countries.[15,16] The assessments include clinician-reported breathlessness and other unique physical and psychosocial domains, which allow us to investigate associations of breathlessness with novel covariates that have not been previously explored. For instance, the tools measure decline in social activities and caregiver distress, which may be associated with breathlessness,[11] yet this has not been studied at a population level.

The aim of this study is to describe the prevalence patterns of breathlessness across Canada, and to identify the clinical and demographic characteristics associated with breathlessness, among a cohort of those requiring long-stay home care or nursing home care.

Methods

Study Design and Population

This is a retrospective observational cohort study using prospectively collected intake assessment data from the interRAI Home Care Reporting System (RAI-HC) and interRAI Nursing Home MDS 2.0 between

January 1, 2007 and December 31, 2018. During this time, the RAI-HC and MDS 2.0 was used across Canada in 9 provinces and territories, including Ontario, British Columbia, Yukon Territories, New Brunswick, Newfoundland, Nova Scotia, Alberta, Saskatchewan and Manitoba. To be included in the study, individuals had to have received long-stay home care services (initial assessment) and/or be admitted to a nursing home (admission assessment). The databases were not mutually exclusive.

Data Sources

The RAI-HC is a clinician-reported standardized assessment tool given to adults expected to receive home care for 60 days or longer. It is completed in the patient's home by a trained clinician (typically a registered nurse). Upon an in-depth interview with the patient, the clinician assesses and reports whether symptoms are present or not based upon information given by the patient themselves, their clinical observations, and discussion with family members or other clinical team members. The assessment is repeated in increments of approximately six to 12 months, upon discharge from an acute inpatient hospital stay, or when a change in health status warrants an earlier re-assessment[17]; thus patients can have multiple assessments completed. Assessments include, but are not limited to, items that measure the patient's functional status, psychosocial well-being, physical health, and care needs.[18] There have been multiple studies that attest to the reliability and validity of items within the RAI-HC.[19-22]

The MDS 2.0 is a standardized clinical assessment that examines roughly 300 items from 15 health domains to comprehensively describe nursing home resident characteristics. These include socio-demographic variables, clinical characteristics, physical and cognitive status, medical diagnoses, major health problems and symptoms, current service use, and prescribed medications.[13,23] The instrument has established psychometric properties,[14,24,25] and has been used in many large scale studies.[26-28] It has been implemented in Canadian nursing homes across multiple provinces as well as internationally.[29,30] In Canada, the MDS 2.0 is used to assess all residents upon admission and every 3 months (quarterly) thereafter until discharge or death.

Outcomes

Presence of breathlessness was measured using a single question asking whether the patient experienced shortness of breath or not (yes/no), and has been used in prior dyspnea research.[31,32] This corresponds with item K3e in the home care assessment and item J1L in the nursing home assessment.

Covariates

The interRAI assessment had several items and scales that were of interest for the study. In addition to sex and age (at most recent assessment), the below items were reported in both the home care and nursing home interRAI assessments, unless otherwise stated. Note, the first 6 were included in the multivariate regression, while all 8 were reported cross-sectionally over calendar time:

1. High pain: Pain level was measured using the Pain Scale, which contained 2-items; the first related to pain frequency and the second to pain intensity. Each item was scored from 0 (*no pain*) to 3 (*daily, severe pain*).[33] High pain was defined as a Pain Scale score of ≥2.

2. Signs of depression: defined when patient exhibits signs of depression indicated using the Depression Rating Scale (DRS) with a score of 3 or more (scale scored from 0-14).[34] The DRS is a summative score of seven items that are scored from 0-2 (where a 2 is that behaviour occurred on each of the last 3 days, 1 is some of the last 3 days, and 0 is none of the last 3 days). The seven items are: made negative statements, persistent anger with self or others, expressions of unrealistic fears (including non-verbal cues), repetitive health complaints, repetitive anxious complaints, crying/tearfulness, and sad/pained/worried facial expression.
3. Cognitive Impairment: defined as when patient exhibits signs of impairment in cognitive function as measured using the Cognitive Performance Scale with a score of 2 (mild impairment) or more.[35] This means a patient has mild-severe impairment in two or more of the following: decision making, making self understood, eating or short-term memory. The scale is scored from 0 (cognitively intact) to 6 (very severe impairment).
4. Activities of Daily Living (ADL) impairment: was measured using the ADL Self-performance Hierarchy Scale.[36] The ADL Hierarchy scale uses grouped activities of daily living according to stage of impairment. The scale focuses on four ADLs (i.e., personal hygiene, toilet use, locomotion and eating) and ranks the assistance required (from no impairment/independent, at least supervision, limited assistance, extensive assistance, to total dependence). The scale ranges from 0 (no impairment, independent) to 6 (total dependence). In our study, high functional impairment was defined as a score of ≥3 (extensive dependence) out of 6. Specifically, at least extensive assistance in personal hygiene or toilet use (and less than extensive assistance in both eating and locomotion) receives a score of 3.
5. Decline in social activities: was measured using a single-item defined as a positive response to whether the patient experienced a reduction in participation in social, occupational, religious or other preferred activities (yes/no).
6. Caregiver distress: was measured as a single-item defined as to whether the primary caregiver expresses feelings of anger, distress or depression (yes/no). This is only measured in the home care interRAI assessment.
7. Health instability: was measured using the CHESS (Changes in Health, End-stage Disease, Signs and Symptoms) scale.[37] The scale is scored from 0 (no health instability) to 5 (very high health instability), and ≥4 on the CHESS scale was defined as 'high health instability'. A patient receives a score of 1 for having the presence of one of these symptom variables (for example breathlessness, weight loss, dehydration, fluid loss, etc.) up-a maximum of 2; then another 1 point for having the presence of any of these three variables: change in decision making, change in ADL status, or evidence of end-stage disease, i.e., estimated prognosis of less than six months).
8. Instrumental Activity of Living Daily (IAD) impairment: was measured using the IADL Involvement Scale.[38] IADLs include meal preparation, ordinary housework, managing finances, medications, phone use, shopping and transportation. IADLs impairment was defined as a score of ≥14 out of 48. This is only measured in the home care interRAI assessment.

Data Analysis

Descriptive data were tabulated using frequencies and percentages for the measure of breathlessness for each variable in the home care and nursing home datasets. Prevalence of breathlessness and other covariates were examined by year in each dataset respectively. We used univariate and multivariate logistic regression to calculate the odds ratio of having clinician-reported breathlessness at intake. In our database, we were able to control for the following covariates, which have been shown in prior research to be associated with breathlessness: sex, age,[1] Depression Rating Scale,[8] Pain scale,[39] and ADLs.[7] Further, because our nursing home and home care cohorts were expected to differ greatly in cognitive performance, we included this variable in our regression. Lastly, because we were interested in examining how caregiver distress and decline in social activities may be associated with breathlessness, we also included these in our model. We tested covariates for collinearity using Pearson correlation test. Analyses were conducted using SAS Enterprise Guide, version 7.1 (SAS Institute, Cary, NC). Because it is a standardized tool for a minimum data set and required for care provision, there was little missing data. The study was approved by the Hamilton Integrated Research Ethics Board (#3039). The study is reported using the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) framework for observational studies.[40]

Results

Between 2007-2018 across Canada, we identified 1,317,117 and 469,709 individuals from the home care and nursing home datasets respectively. (Table 1) In both cohorts, approximately 60% were women. In the home care cohort, 34% were aged 85+ compared to 49% in the nursing home cohort. Comparing the characteristics between the home care and nursing home cohorts: high pain was reported in 54% vs. 18% respectively; ADL impairment was reported in 17% vs. 68% respectively; and neurological diseases were listed as a major diagnosis in 18% vs. 45% respectively.

The prevalence of breathlessness was 26.0% in the home care population and 8.2% in the nursing home population. Among people with clinician-reported breathlessness in the home care population, there was a high prevalence of other symptoms: 63% had high pain, 25% had signs of depression, and 42% had mild-severe impairments in cognitive performance. Fifteen percent exhibited moderate-severe impairment with ADLs, 23% had caregiver distress and 21% noted decline in social activities. In contrast, among those with clinician-reported breathlessness in the nursing home population: 27% had high pain, 30% had signs of depression, and 61% had mild-severe cognitive impairment, and 20% had any decline in social activities.

From 2007 to 2018, the prevalence of breathlessness increased steadily by nearly 10% in the home care population (22.7% in 2007 to 31.9% in 2018). (Figure 1) In contrast, the prevalence of breathlessness remained consistent in the nursing home population during the same period (7.7% in 2007 and 7.5% in 2018). The increase in breathlessness over the years in the home care cohort persisted in both those who did and did not have functional impairment in ADLs. (Appendix 1) The average age of the cohort increased from 75.1 to 78.3 years old in the home care cohort, and 81.6 to 82.7 years old in the nursing home cohort during the 2007-2018 period.

The other covariates over the years followed the same trajectory pattern as breathlessness. For the home care dataset, the prevalence of virtually all covariates increase by approximately 10% over the 12 years. (Figure 2) For the nursing home dataset, the covariates do not increase over the years, remaining flat, similar to breathlessness in this cohort. (Appendix 2)

In the multivariate regression, we found several covariates that were associated with a higher odds of having clinician-reported breathlessness on initial assessment among both cohorts: being male, older age, having high pain (OR=1.59; 95% CI: 1.58-1.60 [home care] vs. OR=1.64; 95% CI: 1.60-1.68 [nursing home]), having signs of depression (OR=1.39; 95% CI: 1.37-1.40 [home care] vs. OR=1.52; 95% CI: 1.48-1.56 [nursing home]), and any decline in social activities (OR=1.25; 95% CI: 1.24-1.27 [home care] vs OR=1.29; 95% CI: 1.26-1.33 [nursing home]; Table 2). Having mild-severe impairment in cognitive performance was associated with a reduced odds ratio of experiencing clinician-reported breathlessness (OR=0.72; 95% CI: 0.71-0.72 [home care] vs OR=0.57; 95% CI: 0.56-0.58 [nursing home]). Having an ADL Hierarchy Score indicating functional impairment was associated with a *reduced* odds of having clinician-reported breathlessness in the home care cohort (OR=0.80; 95% CI: 0.79-0.81), but an *increased* odds in the nursing home cohort (OR=1.23; 95% CI: 1.20-1.26).

Caregiver distress was only measured in the home care cohort. Among those who reported caregiver distress, 28.3% had clinician-reported breathlessness documented, whereas 52.3% reported high pain. In the multivariate regression, the presence of breathlessness was associated with a greater odds of caregiver distress (OR=1.19; 95% CI: 1.18-1.20), controlling for other covariates.

Discussion

The prevalence of breathlessness is higher in the home care population (26%) when compared to the nursing home population (8%). Between 2007-2018, we found a steady increase of 10% in the prevalence of breathlessness in the home care population while the prevalence has remained consistent in the nursing home population. The presence of clinician-reported breathlessness was associated with higher odds of decline in social activities and caregiver distress in the home care population. To our knowledge, this is first study examining the prevalence of breathlessness in a population-based home care and nursing home population.

Our findings that breathlessness was associated with signs of depression is consistent with prior research.[1,7,8] As well, other studies showed worsened function, measured using the modified-Karnofsky scores, was associated with breathlessness.[7,8] This was similar in our nursing home cohort, but different in the home care cohort, where functional impairment was protective of reporting breathlessness. This may be because community-dwelling adults who are functionally impaired are not as active and mobile, and thus less likely to develop exertion-related breathlessness. This may also explain why the prevalence of breathlessness in the nursing home cohort (8%) is markedly lower than that of the home care cohort (26%), since the former cohort has a much older population with a higher proportion with functional impairment, and thus less likely to be actively mobile than the latter. One study of older adults showed a reduction in the frequency of breathlessness in the oldest old, perhaps because they had lived longer having not previously died of chronic conditions causing breathlessness, like heart disease, lung disease or cancer.[1] Moreover, the nursing home cohort had a much larger proportion of individuals with neurological conditions (e.g. Alzheimer's or dementia), which may make it harder to indicate breathlessness.

Our data also include pain, caregiver distress, and decline in social activities. Our regression showed that in the presence of breathlessness, the odds of each of these increased approximately 60%, 19%, and 25% respectively. One explanation of these associations are that being breathless leads to more caregiver distress and greater social isolation due to physical restrictions reflected in decline in social activities.[11,41] The co-existence of breathlessness and pain – and both related to physical exertion - reflect two highly prevalent symptoms in the community which may be causally related.[3,42] However, because these results are cross-sectional, the potentially bi-directional nature of these associations require further investigation.

Our cross-sectional data also shows how the prevalence of breathlessness in the home care population has worsened over the years: the 10% increase in prevalence of breathlessness between 2007-2018 corresponds with a similar 10% worsening of other covariates, such as pain, cognitive impairment, etc. Moreover, the increase persists even looking at those with and without functional impairment. While age may partially explain this trend (the average age in the home care cohort increased from 75 to 78 over the years) since breathlessness increases in older populations,[43,44] in the home care population, both the needs may be increasing in medical complexity and the proportion who require home care supports may be increasing.[45,46]

Limitations of the study include the cross-sectional nature of the initial assessment. This prevents descriptions of longitudinal breathlessness for individuals within these cohorts. It also prevents the examination of incident breathlessness during their home care or nursing home journey, which is planned for future work. We were not able to link the data to hospital data or death date. We also could not link the home care data to long-term care data, so the databases are not mutually exclusive. Symptom covariates are recorded by the provider during the intake assessment interview with the patient, but are not completed directly by the patient. As such, there may be differences between patient-reported symptoms versus clinician-reported symptoms,[47] although fair to good agreement for key symptoms such as pain and breathlessness have been reported.[48] Finally, breathlessness at rest was indicated as a dichotomous variable (yes/no), which does not account for the many dimensions of this complex condition or its scaled intensity.[49,50]

In conclusion, in our national study of Canadian patients, the prevalence of clinician-reported breathlessness was 26.0% in the home care population and 8.2% in the nursing home population. This may be due to the difference in age and levels of ADL impairment. Between 2007 to 2018, there was a consistent increase by 10% (reaching 32% in 2018) in the prevalence of breathlessness in the home care population, whereas the prevalence of breathlessness has remained consistent in the nursing home population. Clinician-reported breathlessness was associated with having high functional ADL impairment, higher pain, greater odds of signs of depression, higher rates of caregiver distress, and greater odds of decline in social activities.

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