Care Practices and Health-related Quality of Life for Individuals Receiving Assisted Ventilation

A Cross-National Study

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Abstract

Rationale: Comparisons of home mechanical ventilation services have demonstrated considerable regional variation in patient populations managed with this therapy. The respiratory care practices used to support individuals receiving assisted ventilation also appear to vary, but they are not well described. It is uncertain whether differences in the approach to care could influence health outcomes for individuals receiving assisted ventilation.

Objectives: We sought to identify and describe the respiratory care practices of home ventilation providers in two different regions and determine whether care practice differences influence health-related quality of life.

Methods: We conducted a cross-national survey of individuals receiving assisted ventilation managed by two statewide home mechanical ventilation providers, one in Victoria, Australia, and the other in British Columbia, Canada. The survey was used to evaluate care practices, functional and physical measures, socioeconomic attributes, and health-related quality of life.

Measurements and Main Results: Overall, 495 individuals receiving assisted ventilation (57.2%) responded to the survey. Responders had clinical attributes similar to those of nonresponders. The Canadian population had a greater proportion of individuals with neuromuscular disorders and lesser percentages with obesity hypoventilation syndrome and chronic obstructive pulmonary disease. We also found marked differences in the reported care practices in Canada that were not fully explained by population differences. Subjects in the Canadian sample were more likely than their Australian counterparts to use invasive mechanical ventilation (24.2% vs. 2.5%; $P < 0.001$), to use routine airway clearance techniques (28.9% vs. 14.8%; $P < 0.001$), and to have had home implementation of noninvasive ventilation (39.9% vs. 3.6%; $P < 0.001$). Subjects in the Australian population were more likely than those in Canada to have undergone polysomnography to evaluate their ventilatory support (93.9% vs. 37.4%; $P < 0.001$). There was no difference in summary measures of health-related quality of life between the two sites. In a multivariable regression model, age, ability to perform activities of daily living, physical function, employment, and household income were all independently associated with health-related quality of life, but neither geographic location (Canada vs. Australia) nor underlying diagnosis were significant factors in the model.

Conclusions: In two cohorts of individuals receiving assisted ventilation, one in Australia and the other in Canada, we found marked differences in both the care practices employed and the populations served. Despite these regional differences, measures of health-related quality of life were not different. Further research is required to examine costly or burdensome interventions that are currently used routinely in the management of individuals receiving assisted ventilation.

Keywords: noninvasive ventilation; quality of life; respiratory insufficiency

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Although the benefits of home mechanical ventilation have been established for people with a number of clinical conditions (1–5), a lack of consensus remains for others (6–9). Consequently, there are marked differences in patient selection for home mechanical ventilation, with regional differences highlighted in previous studies (10–12). Regional variations in approach appear to extend further than simply patient selection, however, with descriptions in published reports suggesting that a wide range of techniques are used to implement, support, and monitor patients receiving assisted ventilation (1). Whether this variation is purely a function of differences in the underlying patient populations or if it represents a true variation in clinical practice is unclear. Would a person using assisted ventilation receive similar care in Europe, North America, and Australasia? And how would any differences in care influence their health-related quality of life (HRQoL)?

A number of care practices appear to be used frequently in some settings and sparingly in others. Examples include the use of polysomnography (PSG) in the implementation and monitoring of noninvasive ventilation (NIV) (11), regular lung volume recruitment or assisted coughing (13), and domiciliary invasive mechanical ventilation in patients with progressive neuromuscular disorders (NMDs) and chronic obstructive pulmonary disease (COPD) (10, 12). Many of these care practices are supported by relatively limited evidence apart from observational data and expert opinion (13–19). A lack of clarity regarding the true clinical impact of these and other care practices would appear to be a significant impediment to more widespread use, and possibly to more consistent and higher-quality care.

In this study, we undertook a cross-sectional assessment of respiratory care practices and HRQoL across two cohorts of individuals receiving assisted ventilation, one in Australia and the other in Canada. These countries share an aspiration to provide universal health care, have similar health care costs per capita, and have approximately 70% of their total health system spending covered by public funding (20). We surveyed individuals receiving assisted ventilation managed by the Victorian Respiratory Support Service, based in Victoria, Australia, and the Provincial Respiratory Outreach Program, in British Columbia, Canada. Both services are publicly funded; are affiliated with large public hospitals (in Melbourne, Australia, and Vancouver, Canada); and offer a state- or province-wide, interprofessional, team-based approach to care that incorporates an outreach service, 24-hour telephone support, ambulatory models for elective NIV implementation, and transition to domiciliary ventilation for hospital inpatients. Despite a number of similarities, anecdotally the two services have developed different models of care in the way that they treat, monitor, evaluate, and support individuals receiving assisted ventilation. Further descriptions of the two services are provided in the online supplement.

Our aims in this study were to describe the two populations of individuals receiving assisted ventilation and identify and characterize differences in care practices between the two sites, as well as to determine whether any identified differences were related to variations in the underlying patient populations or were truly reflective of alternative approaches to care. We also aimed to determine whether differences in care practices between the two sites influenced the HRQoL of individuals receiving assisted ventilation. Previous cross-sectional examinations of HRQoL in similar populations have suggested that underlying diagnosis is a major influence on HRQoL (21, 22). However, these studies did not consider factors that might support or impair HRQoL, such as physical functional status and socioeconomic attributes. Therefore, we also aimed to determine if the association between diagnosis and HRQoL remained after adjustment for these factors.

Methods

The study protocol was approved by the University of British Columbia Clinical Research Ethics Board (H12-01479) and the Austin Health Research Ethics Committee (H2012/04850). Informed consent was obtained from all participants.

Home Mechanical Ventilation Providers

Participants in this cross-sectional study were recruited from two home mechanical ventilation providers, one based in Victoria, Australia, and the other in British Columbia, Canada. We identified participants by accessing the centralized databases of their respective home mechanical ventilation providers. All those receiving home mechanical ventilation as of February 2013 were invited to participate. We collected responses from English-speaking recipients of the postal survey who were able to provide consent. Further details on the survey procedures are included in the online supplement.

Study Questionnaire

Before being sent to participants, the study questionnaire was developed by the investigators and piloted with a small group of individuals receiving assisted ventilation in order to ensure the terminology and format were acceptable.

The questionnaire included items to capture the type and duration of, as well as the reason for, home mechanical ventilation. Data from the client databases were used to supplement questionnaire responses. Specific questions regarding aspects of care (site and circumstances of initial implementation of home mechanical ventilation, completion of advanced care plans, use of routine airway clearance techniques [including lung volume recruitment and assisted cough], and previous PSG while using home mechanical ventilation) were also included. Items used to evaluate demographic and socioeconomic information were adapted from examples obtained from the 2010 U.S. Census.

We also included the Assessment of Quality of Life questionnaire (AQoL-8D) (23), which is a generic, 35-item HRQoL instrument that incorporates eight domains of health and produces a global health utility index anchored at 0.0 (death) and 1.0 (full health). Australian weights were used for the AQoL-8D utility, as Canadian weights were not available. We also included the English translation of the Severe Respiratory Insufficiency (SRI) questionnaire (24), which is a

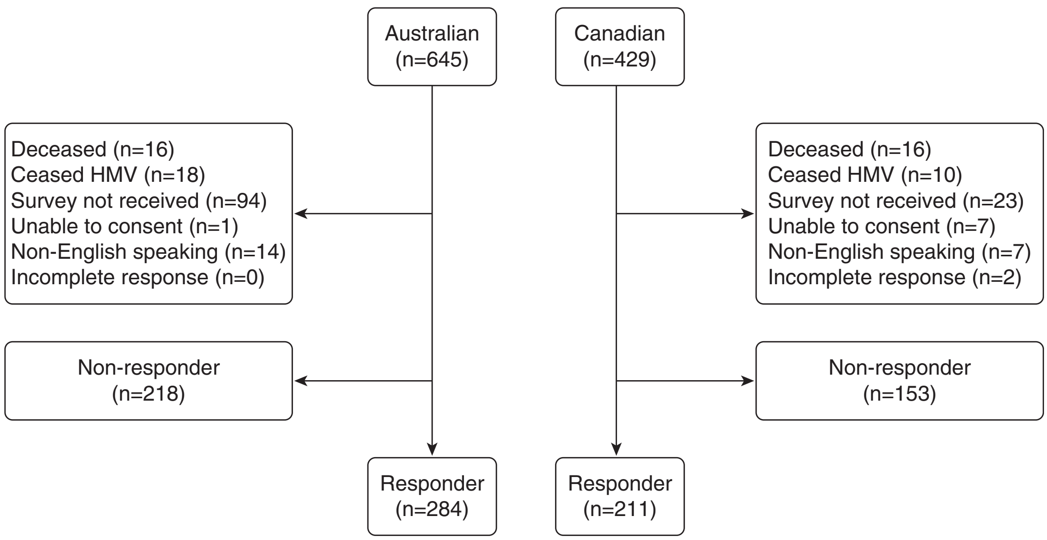

Figure 1. Participant flow through the study. The Australian cohort was derived from the Victorian Respiratory Support Service, Victoria, Australia. The Canadian cohort was derived from the Provincial Respiratory Outreach Program, British Columbia, Canada. HMV = home mechanical ventilation.

disease-specific, multidimensional HRQoL questionnaire designed for use with individuals receiving assisted ventilation (22, 24).

Physical function and independence in activities of daily living (ADL) were evaluated using the Physical Function subscale of the SRI (SRI-PF) (24) and the Katz ADL scale (25), respectively. The Katz ADL scale is a six-item instrument used to measure level of independence (1 point) or dependence (0 points) for each of six basic ADLs: bathing, dressing, toileting, transferring, continence, and feeding (25). Lower scores represent greater dependence on others for basic ADL tasks.

Table 1. Summary of socioeconomic attributes and diagnosis, by site

Characteristic	Australia (*n* = 284)	Canada (*n* = 211)
Age, yr, mean ± SD	56.3 ± 15.0	56.0 ± 16.9
Male sex	55.6%	58.3%
Socioeconomic attributes		
Population center ⩾100,000	160 (56.3%)	106 (50.2%)
Employed or self-employed	38 (13.4%)	29 (13.7%)
Household income ⩾$60,000	45 (15.8%)	59 (30.3%)*
Higher than secondary education level	104 (36.6%)	96 (45.9%)
Residential care	17 (6.0%)	15 (7.1%)
Diagnosis		
ALS/MND	18 (6.3%)	33 (15.6%)*
NMD	105 (37.0%)	132 (62.6%)*
RTD	34 (12.0%)	23 (10.9%)
OHS	88 (31.0%)	17 (8.1%)*
COPD	31 (10.9%)	6 (2.8%)*
Other	8 (2.8%)	0 (0.0%)

Definition of abbreviations: ALS/MND = amyotrophic lateral sclerosis/motor neuron disease; Australia = Victorian Respiratory Support Service, Victoria, Australia; Canada = Provincial Respiratory Outreach Program, British Columbia, Canada; COPD = chronic obstructive pulmonary disease (includes COPD, non–cystic fibrosis bronchiectasis, cystic fibrosis, and overlap syndrome [COPD with obstructive sleep apnea]); NMD = neuromuscular disorders (includes muscular dystrophies, phrenic nerve dysfunction, post-polio syndrome, spinal cord injury, and congenital and acquired neuropathies and myopathies); OHS = obesity hypoventilation syndrome; RTD = restrictive thoracic disorders (includes congenital and acquired kyphoscoliosis, posttuberculous and postsurgical).
*$P < 0.05$.

Statistical Evaluation

Statistical calculations were performed using IBM SPSS version 21 (IBM, Armonk, NY) and Excel 2007 (Microsoft, Redmond, WA) software. Summary statistics were generated using Pearson's χ^2 test for proportions, Student's t test and analysis of variance for comparison of means, and the Mann–Whitney U test for nonnormally distributed data. Using pooled data from both sites, we constructed a forward stepwise multivariable regression model to determine which factors were independently associated with HRQoL (*see* Figures E1 and E2 in the online supplement for details of the model construction). Selection of variables entered in the model was based on factors expected to influence HRQoL in healthy populations and in individuals receiving assisted ventilation, as well as on factors associated with HRQoL measures based on our summary statistics.

Results

In February 2013, 1,074 individuals receiving assisted ventilation were identified across both sites (Australia, n = 645; Canada, n = 429) (*see* Figure 1). Of these, 208

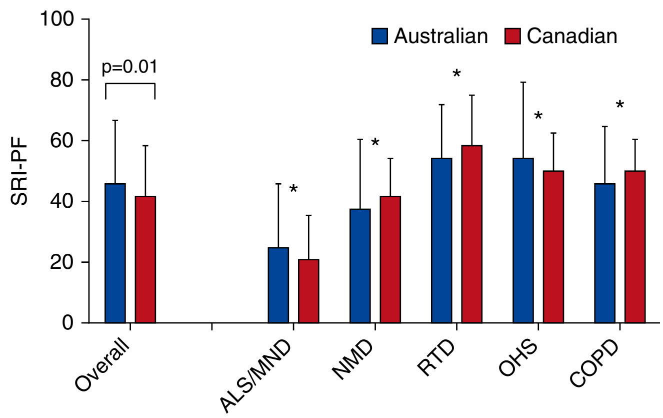

Figure 2. Severe Respiratory Insufficiency questionnaire physical function domain (SRI-PF) comparison, overall and by diagnosis. The Australian cohort was derived from the Victorian Respiratory Support Service, Victoria, Australia. The Canadian cohort was derived from the Provincial Respiratory Outreach Program, British Columbia, Canada. *$P > 0.05$ (not significant). ALS/MND = amyotrophic lateral sclerosis/motor neuron disease; COPD = chronic obstructive pulmonary disease; NMD = neuromuscular disorders; OHS = obesity hypoventilation syndrome; RTD = restrictive thoracic disorders.

individuals were unable to participate in the study, with the predominant reason being failure to receive the postal questionnaire (Figure 1). Of the 866 remaining potential participants, responses were received from 284 at the Australian site (56.6%) and 211 at the Canadian site (58.0%).

Comparison of Responders and Nonresponders

Responders were older than nonresponders at both sites, and responders from the Australian site were more likely than nonresponders from that site to have NMDs as their underlying diagnosis (*see* Table E1). No other significant differences between responders and nonresponders were identified.

Socioeconomic Attributes

Participants from both sites had similar socioeconomic attributes, although participants from Canada were more likely to have a household income (in local currency $CAD or $AUD) of $60,000 or more (Table 1).

Diagnoses

Significant between-site differences were noted with respect to underlying diagnoses. A greater proportion of individuals at the Canadian site had amyotrophic lateral sclerosis/motor neuron disease (ALS/MND) or NMDs, whereas a greater proportion at the Australian site had COPD or obesity hypoventilation syndrome (OHS).

Physical and ADL Function

Canadian participants were more likely to report an inability to complete most basic ADL tasks independently (Katz ADL scores of 0–2) than were those from Australia (46.4% vs. 25.0%, respectively; $P < 0.001$), and they also had a lower median SRI-PF (41.7 vs. 45.8; $P = 0.01$). However, when analyzed within diagnostic categories, no significant difference was observed between sites with regard to these physical function measures, suggesting that they were entirely attributable to the excess of individuals in the Canadian cohort who had NMDs or ALS/MND (*see* Figure 2).

Care Practices

Overall, individuals receiving assisted ventilation in Canada were more likely to use invasive ventilation (24.2% vs. 2.5%; $P < 0.001$), to require daytime ventilation (23.7% vs. 8.1%; $P < 0.001$), to have completed an advanced care plan (27.7% vs. 18.3%; $P = 0.02$), to routinely use airway clearance techniques (28.9% vs. 14.8%; $P < 0.001$), and to have had home mechanical ventilation implemented while

Table 2. Comparison of care practices, overall and by diagnosis

Care Practice	Overall		ALS/MND		NMD		RTD		OHS		COPD	
	Can (*n* = 211)	Aus (*n* = 284)	Can (*n* = 33)	Aus (*n* = 18)	Can (*n* = 132)	Aus (*n* = 105)	Can (*n* = 34)	Aus (*n* = 23)	Can (*n* = 17)	Aus (*n* = 88)	Can (*n* = 6)	Aus (*n* = 31)
Invasive mechanical ventilation	24%	2%*	18%	0%	33%	7%	4%	0%	6%	0%	0%	0%
Polysomnography	37%	94%*	18%	100%	38%	95%	46%	97%	56%	92%	50%	87%
Advanced care plan	28%	18%*	57%	60%	23%	22%	24%	10%	19%	11%	20%	28%
Routine airway clearance techniques	29%	15%*	39%	17%	33%	23%	13%	12%	12%	7%	0%	16%
Home NIV implementation	40%	4%*	64%	0%	35%	4%	52%	0%	13%	6%	50%	3%

Definition of abbreviations: Advanced care plan = active/current advanced care plan; ALS/MND = amyotrophic lateral sclerosis/motor neuron disease; Aus = Victorian Respiratory Support Service, Victoria, Australia; Can = Provincial Respiratory Outreach Program, British Columbia, Canada; COPD = chronic obstructive pulmonary disease; Home NIV = home implementation/initiation of noninvasive ventilation; NMD = neuromuscular disorders; OHS = obesity hypoventilation syndrome; Polysomnography = polysomnography while using assisted ventilation; Routine airway clearance techniques = routine/regular performance of airway clearance techniques (includes airway suctioning, lung volume recruitment, and other assisted cough techniques) in the absence of respiratory infection/deterioration in symptoms; RTD = restrictive thoracic disorders.
Invasive mechanical ventilation refers to assisted ventilation delivered via tracheostomy or endotracheal tube.
*$P < 0.05$.

Table 3. AQoL-8D health utility and domain health utility values, by site

	Australian		Canadian		*P* Value
	Median	IQR	Median	IQR	
Health utility	0.56	0.41–0.77	0.56	0.43–0.73	0.59
Mental SD	0.29	0.18–0.44	0.31	0.19–0.43	0.84
Physical SD	0.48	0.34–0.62	0.44	0.31–0.53	0.01
IL	0.52	0.42–0.71	0.46	0.37–0.58	<0.001
H	0.75	0.63–0.85	0.79	0.63–0.85	0.81
MH	0.60	0.51–0.71	0.63	0.51–0.71	0.39
C	0.77	0.61–0.85	0.77	0.61–0.85	0.97
R	0.57	0.51–0.74	0.58	0.51–0.71	0.59
SW	0.76	0.63–0.89	0.76	0.63–0.89	0.97
P	0.71	0.46–0.95	0.71	0.42–0.85	0.83
S	0.84	0.75–0.92	0.82	0.73–0.92	0.18

Definition of abbreviations: AQoL-8D = Assessment of Quality of Life-8D; Australian = Victorian Respiratory Support Service, Victoria, Australia; Canadian = Provincial Respiratory Outreach Program, British Columbia, Canada; C = coping; H = happiness; IL = independent living; IQR = interquartile range; MH = mental health; P = pain; R = relationships; S = senses; SD = super-dimension; SW = self-worth.

at home (rather than in a hospital or a sleep laboratory) (39.9% vs. 3.6%; $P < 0.001$) (*see* Figure 3 and Table 2). Those managed by the Australian service were significantly more likely to have undergone PSG to evaluate their home mechanical ventilation therapy (93.9% vs. 37.4%; $P < 0.001$), with differences in the use of PSG persisting even after we analyzed only those individuals who were prescribed nocturnal NIV (93.3% vs. 42.3%). The differences in care practices (with the exception of advanced care plans) remained significant after adjustment for underlying diagnosis, suggesting that they represented different approaches to care between the two home mechanical ventilation providers (*see* Table 2). The reported frequency of contact with health care workers and the number of hospital admissions in the previous 12 months were not different between the two sites.

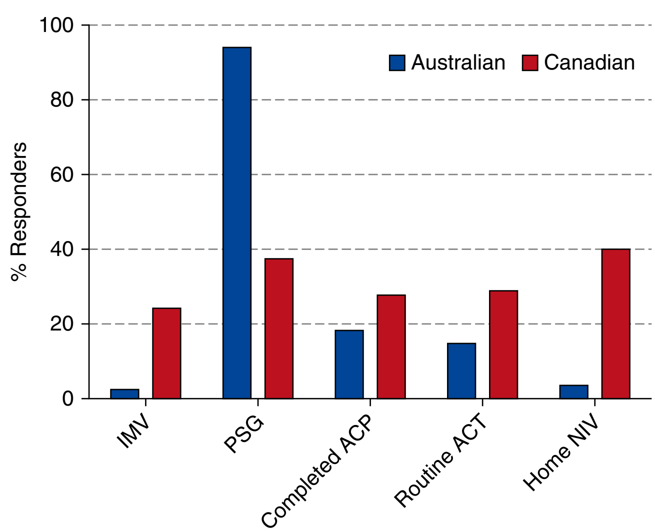

Figure 3. Care practices of home mechanical ventilation providers (all responders). The proportion of all of the displayed care practices (IMV, PSG, ACP, ACT, and Home NIV) were significantly different between the two home mechanical ventilation providers ($P < 0.05$). The Australian cohort was derived from the Victorian Respiratory Support Service, Victoria, Australia. The Canadian cohort was derived from the Provincial Respiratory Outreach Program, British Columbia, Canada. Completed ACP = active advanced care plan; Home NIV = home implementation/initiation of noninvasive ventilation; IMV = invasive mechanical ventilation; PSG = polysomnography (while using assisted ventilation); Routine ACT = routine/regular performance of airway clearance techniques (includes airway suctioning, lung volume recruitment and other assisted cough techniques) in the absence of respiratory infection/deterioration in symptoms.

Health-related Quality of Life

Despite the significant differences identified in both the reported care practices and the underlying diagnoses within the two cohorts, there was no overall difference in AQoL-8D health utility between the two sites (Table 3). There also were no differences in subgroups separated by sex, diagnosis, or home mechanical ventilation type (Table 3 and Figure 4).

Regarding the domains of the AQoL-8D, Canadian participants had lower scores than their Australian counterparts in the Physical super-dimension and Independent Living domain of the AQoL-8D, but this did not translate to significant differences in health utility. When these domains of the AQoL-8D were analyzed according to diagnostic groups, the differences between the two sites were not significant, again suggesting that they were a result of the excess number of individuals within the Canadian cohort who had NMDs or ALS/MND.

The results were similar when we used the disease-specific HRQoL instrument (*see* online supplement): We found no differences between sites in either the SRI summary scale or the domains of the SRI, with the exception of the SRI-PF differences outlined previously.

Multivariable Regression

For the AQoL-8D health utility, the final multivariable model included measures of physical function and ADL performance (SRI-PF and Katz ADL scale) as well as measures of socioeconomic status (annual household income [⩾$60,000] and employment [for wages]) and age (Tables 4 and 5). The final model explained 44.9% of the variance of the AQoL-8D health utility. Neither underlying diagnosis nor site of care (Australia vs. Canada) was independently associated with either measure of

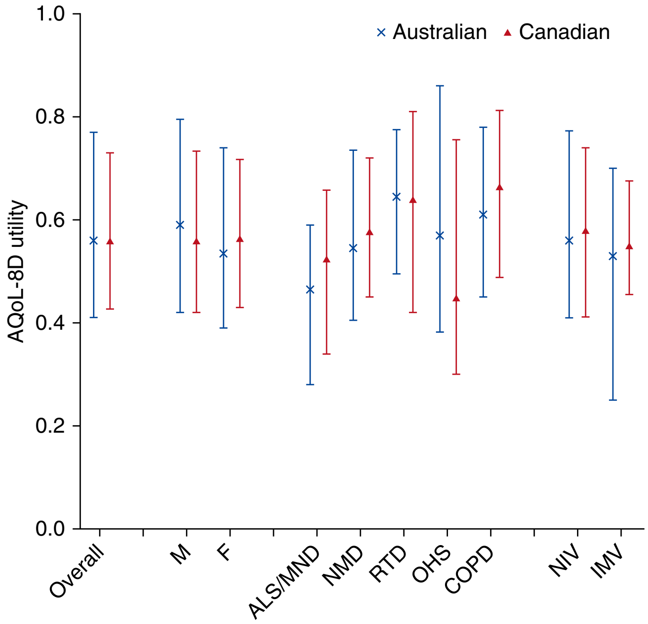

Figure 4. Assessment of Quality of Life-8D (AQoL-8D) health utility results, by site, sex, diagnosis, and home mechanical ventilation type. The Australian cohort was derived from the Victorian Respiratory Support Service, Victoria, Australia. The Canadian cohort was derived from the Provincial Respiratory Outreach Program, British Columbia, Canada. *Triangles* and *crosses* indicate the median values. The error bars indicate the interquartile ranges. There were no significant between-site differences overall or for any of the subgroups (all $P > 0.05$). ALS/MND = amyotrophic lateral sclerosis/motor neuron disease; COPD = chronic obstructive pulmonary disease; F = female; IMV = invasive mechanical ventilation; M = male; NIV = noninvasive ventilation; NMD = neuromuscular disease; OHS = obesity hypoventilation syndrome; RTD = restrictive thoracic disorders.

HRQoL in the multivariable model (Figures E1 and E2). Figure 5 illustrates the apparent lack of influence of diagnosis on AQoL-8D health utility following adjustment for the factors contained within the final model.

Discussion

This cross-national, cross-sectional study demonstrated marked regional differences in the clinical characteristics of individuals receiving assisted ventilation and the care practices used to support them. Yet, in spite of these differences, HRQoL was not different between the two sites.

There were significant differences between the Canadian and Australian services in the proportions of clients who had NMDs (including ALS/MND), OHS, and COPD. Data to confirm that the prevalence of these disorders is similar within the two general populations are limited (26–32); however, on the basis of available studies, the differences in proportions we found seem to exceed what could reasonably be expected. In addition, there were also considerable differences in the proportions of individuals using invasive ventilation, and undergoing PSG, home implementation of NIV, or using routine airway clearance techniques. These differences in care practices were not simply the result of the variation in underlying diagnoses between sites, as they persisted when analyzed according to diagnostic groupings. This suggests that both patient selection and care practices differ between these two otherwise very similar home mechanical ventilation services - despite their location within predominantly publicly funded health care systems and within countries with considerable socioeconomic similarities (20–22). Yet, despite these clear variations in approach, we did not observe any difference in summary measures of HRQoL, either overall or by diagnosis.

Domiciliary mechanical ventilation has now been used for over 50 years, and yet the methods and manner in which it is used continue to vary according to region. Our study is certainly not the first to identify some of these regional variations in approach (10, 11). Patient selection has undoubtedly been the most apparent aspect of differences in previous studies. In the Eurovent study, Lloyd-Owen and coworkers demonstrated considerable differences between European countries with regard to both the prevalence of home mechanical ventilation and the proportions of those treated who had COPD and NMDs (10). In a subsequent article, Garner and colleagues compared home mechanical ventilation services in Australia and New Zealand and reported significant differences between these two countries in the proportions using assisted ventilation who had NMDs, OHS, restrictive thoracic disorders, and COPD. Some regional differences in care practices have also been described (10, 11, 35), with Garner and coworkers highlighting the more frequent use of PSG to implement therapy in Australian centers.

We postulate that the primary drivers of the differences demonstrated in these studies and in our data are cost (or access) constraints, a relative lack of evidence or conflicting evidence regarding certain approaches, and a historical or philosophical preference for certain techniques. Cost and access constraints are the most straightforward of these to consider, as these factors tend to influence most aspects of health care provision. Ambulatory care models (including implementation of NIV in the home) are an example of a potentially lower-cost model for the implementation of home mechanical ventilation. Although a number of home mechanical ventilation services still use inpatient stays to implement and review therapy (8), in selected patients, ambulatory care models appear to provide equivalent clinical outcomes and are associated with fewer delays (36, 37). Another aspect of care that is driven by cost is the use of invasive ventilation. Financial incentives (or disincentives) for this form of therapy differ by region (10) and may be dependent on the method of funding (public or private) and the capacity of community services to safely manage these patients. Financial incentives could also influence the use of certain

Table 4. Univariable regression estimates of effect

Factors Associated with AQoL-8D Health Utility	AQoL-8D		
	β Value	Range	*P* Value
Age	0.0*	(−0.01 to 0.01)	0.9
Sex	0.03	(−0.01 to 0.07)	0.12
Labor force participation	0.12	(0.07 – 0.17)	<0.001
Diagnosis			0.01
ALS/MND	−0.10	(−0.25 to 0.06)	
NMD	−0.02	(−0.16 to 0.13)	
RTD	0.06	(−0.10 to 0.21)	
OHS	−0.01	(−0.16 to 0.14)	
COPD	0.03	(−0.13 to 0.19)	
Other	0		
Katz ADL scale score			<0.001
6	0		
3–5	−0.16	(−0.20 to 0.11)	
0–2	−0.12	(0.16–0.08)	
SRI physical function	0.06*	(0.04–0.07)	<0.001
Employment for wages	0.15	(0.10–0.21)	<0.001
Household income ⩾$60,000	0.06	(0.01–0.10)	0.01

Definition of abbreviations: ADL = activities of daily living; ALS/MND = amyotrophic lateral sclerosis/motor neuron disease; AQoL-8D = Assessment of Quality of Life-8D; COPD = chronic obstructive pulmonary disease; NMD = neuromuscular disorders; OHS = obesity hypoventilation syndrome; RTD = restrictive thoracic disorders; SRI = Severe Respiratory Insufficiency questionnaire.
*β value for a change in the parameter equal to 0.5 of the standard deviation of that parameter (age = 0.5 × SD = 7.9 yr; SRI-PF = 0.5 × SD = 11.6).

investigations or procedures in some settings (38). The ability to access dedicated units with the aim of removing patients from invasive mechanical ventilation may also influence both the number of patients managed with invasive ventilation during acute illnesses and the numbers downstream who need to be managed in this way in the community (39–42).

A lack of conclusive evidence, as well as conflicting evidence from clinical trials, also underlies some of the regional variation in the use of home mechanical ventilation. Lloyd-Owen and colleagues clearly demonstrated geographic variation in the use of long-term NIV for individuals with COPD, and, in spite of more recent studies suggesting a mortality benefit in this group (8, 9), there remains no clear consensus regarding the role of long-term NIV for this indication. Our data also suggest the presence of regional preferences in the use of NIV for individuals with OHS, and in this area, too, recent evidence does imply that continuous positive airway pressure therapy may provide equivalent benefits to NIV in a significant proportion of those with OHS (5, 43).

Other practices, including the use of long-term invasive ventilation for individuals with progressive neurological disorders (such as ALS/MND), the routine use of airway clearance techniques (including lung volume recruitment and mechanically assisted cough), and the use of PSG (or polygraphy) to evaluate home mechanical ventilation, are supported by observational literature and expert opinion (13–19). However, they appear to be used infrequently by a number of home mechanical ventilation providers, presumably because of a lack of controlled clinical trials. Our results emphasize the need for further research in this area, not only to improve the quality of care but also to ensure that limited resources are used appropriately.

The results of this project provide support for previous qualitative studies that emphasized the importance of physical function and socioeconomic status on the overall HRQoL of individuals receiving assisted ventilation (44–46). In fact, the influence of these factors on HRQoL in our present study appeared to be more important than that of the underlying diagnostic label or the respiratory care practices used. This extends the findings of previous studies in which researchers identified diagnosis as an important predictor of HRQoL in cohorts of individuals receiving ventilator assistance (21, 22). The results of our analysis demonstrate that the differences in HRQoL between diagnostic groups are explained more by physical functional status and socioeconomic factors than by any intrinsic aspect of the diagnosis itself. We acknowledge that the underlying disorder which has contributed to the need for assisted ventilation is likely to be an important determinant of physical function, and possibly socioeconomic status; however, our results suggest that there is no diagnostic category that is intrinsically associated with poor HRQoL

Table 5. Multivariable regression estimates of effect and final model

Factors Associated with AQoL-8D Health Utility	AQoL-8D		
	β Value	Range	*P* Value
Age	0.02*	(0.01–0.02)	0.001
Katz ADL scale score			<0.001
6	0		
3–5	−0.04	(−0.07 to 0.00)	
0–2	0.07	(0.03–0.12)	
SRI physical function	0.07*	(0.06–0.08)	<0.001
Employment for wages	0.06	(0.01–0.10)	0.04
Household income ⩾$60,000	0.04	(0.8–0.01)	0.01
Adjusted R^2 value			0.449

Definition of abbreviations: ADL = activities of daily living; AQoL-8D = Assessment of Quality of Life-8D; SRI = Severe Respiratory Insufficiency questionnaire.
*β value for a change in the parameter equal to 0.5 of the standard deviation of that parameter (age = 0.5 × SD = 7.9 yr; SRI-PF = 0.5 × SD = 11.6).

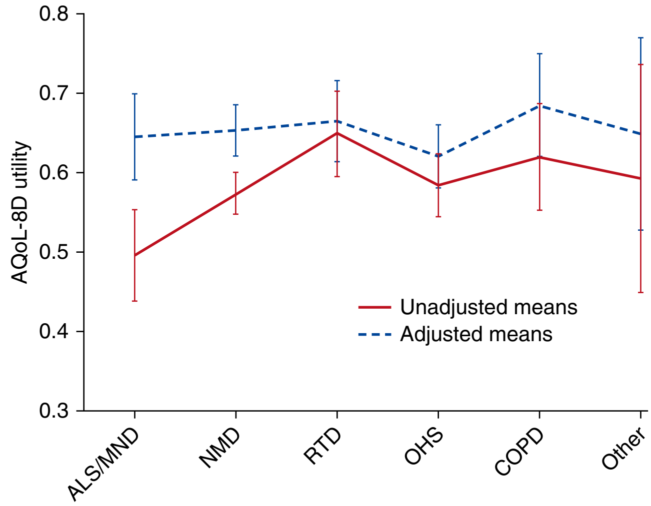

Figure 5. Assessment of Quality of Life-8D (AQoL-8D) health utility results expressed as unadjusted versus adjusted (estimated marginal) mean values, by diagnosis. Unadjusted mean AQoL-8D (mean with 95% confidence intervals) for pooled data from both sites according to diagnosis and compared with adjusted mean AQoL-8D utility (estimated marginal mean with 95% confidence intervals) from the final multivariable model. ALS/MND = amyotrophic lateral sclerosis/motor neuron disease; COPD = chronic obstructive pulmonary disease; NMD = neuromuscular disorders; OHS = obesity hypoventilation syndrome; RTD = restrictive thoracic disorders.

among individuals receiving assisted ventilation.

One interpretation of our data suggests that unemployed, financially insecure, and functionally limited individuals receiving ventilator assistance are likely to have a poor HRQoL, regardless of whether they have a diagnosis of COPD, ALS/MND, or OHS, whereas the reverse is likely to be true for those who are employed, financially stable, and less physically dependent. This finding is important for both patients and clinicians, as there is considerable clinical heterogeneity within these broad diagnostic groups and the decision to commence home mechanical ventilation may be influenced by predictions of HRQoL on treatment. Our data support the use of more holistic assessments to better inform these decisions. Our cross-sectional data do not capture potential differences in the trajectory of HRQoL with different diagnoses; however, longitudinal studies have not consistently demonstrated a diagnosis-related impact on HRQoL trajectory (47, 48).

Given the significant differences identified in both the clinical attributes and the respiratory care practices of the two home mechanical ventilation services, it is somewhat surprising that overall HRQoL was not different, even after adjustment for differences in diagnoses and other important baseline variables. Does this mean that the choice of respiratory care practices does not really matter? Our observational data cannot answer this question conclusively. We examined two well-established, centrally administered, interprofessional home mechanical ventilation providers, and it is possible that these structural similarities, combined with adequate clinical expertise, allow the two models of care to achieve similar outcomes for their patients. Our data suggest a lack of association between the care strategies identified and HRQoL outcomes; therefore, we speculate that, on a population level, the magnitude of benefit obtained from individual strategies aimed at optimizing ventilation and respiratory care may be quite small. We acknowledge, however, that such strategies could be beneficial within smaller subgroups. As such, it is vital that care practices that are employed routinely are carefully and critically evaluated, particularly those that are either costly or burdensome for patients. For example, given the marked difference between the sites in the use of PSG, further evaluation is warranted to evaluate the burden, costs, and clinical impact of this practice.

This study has a number of limitations that require consideration. Although we used evidence-based methods to optimize our response rate (49), we acknowledge the potential for responder bias, particularly the possibility that individuals receiving assisted ventilation with better HRQoL may be more likely to respond to a voluntary postal survey such as ours. Also, we note that the Australian site had more clients who did not receive the postal survey than the Canadian site, although we did not identify any systematic reason for this to have occurred. Reassuringly, our comparison of responders with nonresponders demonstrated that our samples provided a good representation of the respective cohorts.

We also acknowledge that, owing to our use of a postal survey, a caregiver or support person may have assisted with or completed the survey on behalf of some respondents, which may have introduced an unknown degree of bias. Although we evaluated data from two statewide and publicly funded services, some individuals could access privately funded NIV devices and therefore may not have been captured within this study. It is uncertain whether this practice occurs to a degree at either site sufficient to influence our findings, although we do not suspect this to be the case. It is also possible that the outcome measures used may not have been sufficiently sensitive to detect a difference that could be attributed to differences in care practices. We attempted to reduce this likelihood through the inclusion of a disease-specific HRQoL instrument. The results obtained with the SRI were not different from those derived from the AQoL-8D (*see* online supplement); however, this possibility remains. We identified only associations (and the lack thereof) with HRQoL in this study; therefore, these observations should be considered as hypotheses until proven in prospective longitudinal studies. Conducting qualitative studies designed to increase understanding of drivers of patient selection biases at the patient, clinician, organizational, and community levels is also important.

Conclusions

In this study, we found considerable differences between two home mechanical ventilation providers in different regions with regard to both the care practices employed and the populations served. Geographic heterogeneity in patient selection and the methods used to implement, support and monitor individuals receiving assisted ventilation therefore remains an ongoing challenge to clinicians and researchers in this area. Despite these marked differences between the Australian and Canadian services, there appeared to be no influence on HRQoL, either overall or by diagnostic group. This apparent lack of influence on HRQoL highlights a need for further research to examine interventions that are currently used routinely in the management of individuals receiving assisted ventilation, particularly those interventions that are either costly to administer or burdensome to perform. A focus on strategies that can improve the physical function, independence, employment opportunities, and financial security of individuals receiving assisted ventilation may be more beneficial. ■

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