Health-related Quality of Life of Home Ventilated Patients (HoMe V) from a Tertiary Hospital in Singapore

Dear Editor,

Home mechanical ventilation (HMV) is an established treatment of severe chronic respiratory failure from neuromuscular disorders, restrictive thoracic disease, obesity hypoventilation syndrome and chronic obstructive pulmonary disease. Life prolongation, symptom control, and improvement of patient well-being and function are some of the treatment goals. Hospitalisation rate is reduced once HMV is established.[1] HMV patients, however, face unique challenges. HMV may affect a variety of physical and psychological health domains such as respiratory symptoms, limited mobility, anxiety, compromised social interaction and depression. The effects of non-invasive positive pressure ventilation (NIPPV) on patient reported outcomes (PRO) varied depending on the underlying disorder.[2] However, study quality in this area is poor and there remains many uncertainties as to which patient may benefit from HMV and how they may benefit.

Health-related quality of life (HRQoL) is a psychological construct describing the subjectively experienced health status based on various components of health including physical state, psychological well-being, social relations and functional capacities. As an important component of health surveillance, HRQoL has steadily become essential in evaluating the costs and benefits of modern treatment modalities, and a valid indicator of service needs.[3]

International multicentre studies have reported improvement in HRQoL following HMV establishment.[1] An evaluation of HRQoL in HMV patients is timely as multiethnic Singapore is seeing a growing number of HMV patients. A better understanding of HRQoL and factors influencing it is crucial in improving quality of care and optimising clinical outcomes.

The aim of the HoMe V (HRQoL of home mechanical ventilated patients) study is to describe the HRQoL among HMV patients and to evaluate if local outcome measures are comparable to those reported overseas.[1,4] The secondary objective is to determine factors associated with HRQoL.

Materials and Methods

Tan Tock Seng Hospital (TTSH) Home Ventilation and Respiratory Support Service (HVRSS)[5] is the first service in Singapore dedicated to support ventilator-assisted and ventilator-dependent patients in the community. We invited clinically stable patients from TTSH HVRSS who were well adapted to HMV to participate in the study. Participants with cognitive impairment, psychiatric disorders, communication barriers or disabilities, and those unable to comprehend English were excluded.

We conducted phone calls to obtain initial verbal consent and to schedule an appointment for questionnaire administration. Participants were reassessed for medical stability prior to proceeding with written consent. Participants were deemed medically unstable if they had evidence of acute respiratory failure,[6] defined as worsening of symptoms, signs of respiratory infection (any 2 of the following: increasing cough, purulent sputum or fever) or SpO_2 <90 mmHg. Written consent was obtained from medically stable participants on the day of the survey appointment. Participants were withdrawn from the study if they voluntarily dropped out or if their condition deteriorated.

The study was approved by the Domain Specific Review Board (National Healthcare Group).

Questionnaire

The English version of the Severe Respiratory Insufficiency (SRI) questionnaire,[7] a disease-specific, multi-dimensional, self-administrated HRQoL instrument, was used to measure HRQoL. It has good psychometric properties, consisting of 49 questions across 7 domains covering respiratory complaints (RC), physical functioning (PF), attendant symptoms (such as cough and expectoration, headache, dizziness and neck ache) and sleep (AS), social relationship (SR), anxiety (AX), psychological well-being (WB), and social functioning (SF). Subscales are aggregated into one summary score (SS) where higher values indicate higher HRQoL. For data evaluation, values obtained from the questionnaire were scaled from 0 to 100, analogous to computation of percentages. We also included a question, "In view of your experience thus far, would you agree to be on ventilator support if you could decide on your treatment all over again?"

Statistical Analysis

Statistical computation was performed with Statistical

Package for Social Sciences (SPSS Inc., Chicago, IL), version 21. Continuous variables were reported as mean ± standard deviation, unless otherwise stated. Absolute numbers and percentages of each category were used for categorical data. Unpaired student's t-test compared continuous variables. Chi-square test analysed differences between categorical variables. ANOVA test evaluated study differences in continuous variables between categorical variables with more than 2 categories. *P* values <0.05 were considered significant.

Results

We approached 38 eligible participants. Six refused participation. Eight were unable to complete the survey for various reasons: 1 relocated, 3 were unable to schedule, 1 died, and 3 were deemed medically unstable to proceed. Twenty-four (63.2%) gave written consent and completed the questionnaire. Questionnaires were administered in 33.2 ± 13.7 minutes, with 100% response rate for all items. Characteristics of the study population are shown in Table 1. Respiratory complaints scored highest while physical functioning scored lowest. Among the psychosocial domains, social relationships scored highest while social functioning had the lowest score.

Psychometric subscale values and SRI-SS were not significantly different between age groups, genders and ethnic groups. No difference in psychometric scales was observed for educational level, monthly household income, caregiver groups, Charlson-age comorbidity index and HMV duration. Emergency department attendance (25%) and admission rates (37.5%) were low. Modifiable factors associated with HRQoL subscales were route of ventilation. Tracheostomy group (50.69 ± 17.75) scored lower than non-tracheostomy (70.83 ± 15.59) group in terms of social relationship, $P = 0.01$. Tracheostomy group (30.99 ± 15.68) also scored lower in social functioning than non-tracheostomy (61.35 ± 7.48) group, $P = 0.02$.

Participants on HMV for less than 14 hours (59.09 ± 30.76) scored higher than those ventilated for 14 hours or more (37.50 ± 15.53) in social functioning.

Choosing Ventilator Support Again

Thirteen out of 24 (54%) indicated that they would choose ventilator support again if given a second chance. Three (12.5%) were unsure.

Discussion

Generally, a moderate global HRQoL was observed. SS, AS and WB scores for our cohort were comparable with international multisite studies.[1,4,7] Our cohort scored higher for RC and AX as a whole (Table 2). Our holistic and structured delivery of HVRSS with co-interventions such as access to telephone support and home visits could have positively influenced some of the PRO measures.[2]

Nonetheless, differences in patients' characteristics prevailed between our study and previous studies. Our cohort had a predominance of males and Chinese, was younger (mean age 53.2 ± 16.2 years), and spent more time on ventilator (mean duration 15 hours daily) compared to Windisch's cohort[1] of predominantly chronic obstructive pulmonary disease (COPD) and restrictive thoracic disease (RTD) patients with mean age ranging from 53 to 63 years, and who spent 7.3 ± 2.7 hours daily on NIPPV. Ghosh's cohort[7] of inpatients with COPD, RTD and obesity hypoventilation syndrome (OHS) had a mean daily duration of ventilation from 7 to 8 hours; higher (11 hours) for neuromuscular disorders patients who were younger.

In contrast, HVRSS supports largely patients with respiratory muscular dysfunction from neuromuscular dystrophy (NMD), Duchene muscular dystrophy (DMD), and amyotrophic lateral sclerosis (ALS). The local practice where patients tend to be referred for ventilator support later in the disease's trajectory could partly explain the observed differences in daily ventilation time. Research into the knowledge, attitudes and practices of both physicians and patients towards HMV would add to the knowledge to this emerging intervention.

Our PF and SF scores were poor; in keeping with previous reports where scores in these 2 domains were low in neuromuscular disease due to the accompanying disability and handicap from limb weakness.[1] Problems of social integration[8] and perceived stigmatisation[9]—known issues that trouble patients with tracheostomy—could account for the lower SF and SR scores. Non-invasive ventilation may be preferred over invasive support (tracheostomy).[10] However, patients with more severe illnesses are more likely to require invasive ventilation. Hence, the mode of ventilation may not solely account for poorer SF and SR scores.

It is well documented that HRQL is strongly influenced by the underlying disease. In our study, association between daily ventilation time and SF domain was borderline significant after stratifying for primary diagnostic groups. This is likely that our study was underpowered. Notwithstanding, we noted that the associations and trends were largely preserved. Our study's finding was in concordance to Hannan et al[2] where a beneficial PRO is seen in patients with amyotrophic lateral sclerosis/motor neuron disease (ALS/MND). Interestingly, we did not see the same benefit in the RTD group, as reported in systematic review. Our cohort had only 2 participants in the RTD category, and they seemed to have a poorer in in SS score. We speculate that this apparent lack of benefit could be a result of the very small sample in that group.

Table 1. Characteristics of the Study Participants

Continuous Variables	**n**	**%**
Gender		
Male	19	79.2
Female	5	20.8
Age (years)		
<40	7	29.2
40 to 60	8	33.3
>60	9	37.5
Ethnicity		
Chinese	21	87.5
Non-Chinese	3	12.5
Highest education		
Basic (primary, secondary, ITE & equivalent)	16	66.7
Tertiary education (polytechnic & university)	7	29.2
Marital status		
Never married	11	45.8
Ever married (married & divorced)	12	50.0
Employment status		
Employed	18	75.0
Unemployed	5	20.8
Monthly household income		
Less than $1000	9	37.5
$1000 to $4000	12	50.0
$4000 and above	3	12.5
Housing type		
HDB 1- & 3-room	6	25.0
HDB 4-room	6	25.0
HDB 5-room	5	20.8
Maisonette, executive flats/condominium/landed	2	8.3
Others (nursing home)	3	12.5
Main caregiver		
Family members (parents, siblings, spouse, children, daughter-in-law)	6	25.0
Domestic helper	7	29.2
Family & helper	6	25.0
Others (self, friend, nursing home [n = 3])	5	20.8
Primary diagnosis		
Ventilatory muscle disorders*	14	58.4
Tetraplegia	2	8.3
Restrictive lung disease	2	8.3
Others†	6	25.0
Route of ventilation		
Tracheostomy	12	50.0
Non-tracheostomy	11	45.8

ED: Emergency department; HDB: Housing and Development Board; HMV: Home mechanical ventilation; ITE: Institute of Technical Education; SD: Standard deviation

*Neuromuscular disorder (n = 7); Duchene muscular dystrophy (n = 3); Amyotrophic lateral sclerosis (n = 4).

†Anterior spinal cord infarct (n = 1); Becker's musculodystrophy (n = 1); Congenital hypomyelinating disease (n = 1); Mitochondrial myopathy (n = 1); Prolonged ventilation for aspiration pneumonia (n = 1); Spinal muscular atrophy (n = 1).

‡High SRI values indicate better health-related quality of life (HRQoL).

Table 1. Characteristics of the Study Participants (Cont'd)

Categorical Variables	**Mean (SD)**	**Range**
Age	53.2 (16.2)	27 – 78
Charlson-Age Comorbidity Index (CACI)	1.7 (1.5)	0 – 6
Duration of HMV (months)	22.3 (31.5)	0.6 – 116
Hours of HMV per day	15.1 (9.8)	1 – 24
ED attendance past 6 months	0.23 (0.5)	0 – 1
Admissions past 6 months	0.4 (0.6)	0 – 2
Severe Respiratory Insufficiency (SRI) Domain Score‡	**Mean (SD)**	**Range**
Summary score (SS)	56.3 (15.3)	21.8 – 83.5
Respiratory complaints (RC)	70.7 (19.4)	31.3 – 100.0
Physical functioning (PF)	38.5 (20.7)	0.00 – 75.0
Attendant symptoms and sleep (AS)	62.2 (18.2)	35.7 – 100
Social relationship (SR)	61.5 (19.7)	16.7 – 95.8
Anxiety (AX)	60.6 (20.7)	15.0 – 100.0
Psychological well-being (WB)	53.4 (22.8)	5.6 – 86.1
Social functioning (SF)	47.4 (26.3)	9.4 – 100.0

ED: Emergency department; HDB: Housing and Development Board; HMV: Home mechanical ventilation; ITE: Institute of Technical Education; SD: Standard deviation

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Table 2. Comparison of SRI

Authors, Place of Care	**Disease Type**	**Sample Size**	**Mean Age**	**Average Use Per Night (Hour)**	**SRI Scores [Mean (SD)]**							
						Biophysical Domain			**Psychosocial Domain**			
					SS	**RC**	**PF**	**AS**	**SR**	**AX**	**WB**	**SF**
Windisch et al,* home	All	82	-	7.3 (2.7)	61 (16)	-	-	-	-	-	-	-
Lopez et al,† home	All	115	62 (14)	8.6 (3.2)	57.8 (18.5)	61.2 (22.1)	43.2 (26.7)	60.9 (21.6)	76.7 (17.2)	55.9 (24.8)	58.3 (22.7)	54.9 (25.8)
Ghosh et al,‡ hospital	All	152	-	8.4 (3.8)	55.9 (18.9)	52.7 (20.9)	42.2 (22.3)	56.8 (20.5)	70.6 (21.4)	52.3 (27.2)	59.5 (21.3)	60.6 (24.4)
HVRSS, home	All	24	53	15	56.3 (15.3)	70.7 (19.4)	38.5 (20.7)	62.2 (18.2)	61.5 (19.7)	60.6 (20.7)	53.4 (22.8)	47.4 (26.3)

AS: Attendant symptoms and sleep (of SRI); AX: Anxiety (of SRI); HVRSS: Home ventilation and respiratory support service; PF: Physical functioning (of SRI); RC: Respiratory complaints (of SRI); SD: Standard deviation; SF: Social functioning (of SRI); SR: Social relationship (of SRI); SRI: Severe respiratory insufficiency; SS: Summary score (of SRI); WB: Psychological well-being (of SRI)

*Windisch W; Quality of life in home mechanical ventilation study group. Impact of home mechanical ventilation on health-related quality of life. Eur Respir J 2008;32:1328-36.

†López-Campos JL, Failde I, Masa JF, Benítez-Moya JM, Barrot E, Ayerbe R, et al. Factors related to quality of life in patients receiving home mechanical ventilation. Respir Med 2008;102:605-12.

‡Ghosh D, Rzehak P, Elliott MW, Windisch W. Validation of the English Severe Respiratory Insufficiency Questionnaire. Eur Respir J 2012;40:408-15.

A systematic review[11] reported that fewer than half of ventilator-assisted individuals (VAIs) were actively employed, and many caregivers had to reduce or quit work hours to enable care for VAIs. It also highlighted burden in the domains of financial strain, negative impact on employment, and insufficient time for oneself and personal relationships. Despite this, if given a second chance, 80% of caregivers would choose HMV again for their loved ones. In our cohort, 75% were unemployed. Slightly more than half (54%) indicated that they would choose to go on HMV again if they were to be given a second chance.

Strengths and Limitations

To our knowledge, this is the first study of its kind in multiethnic Asian patients. Our study suffered from a lack of statistical power due to its small sample size. Our small sample may not be representative of the population of patients managed by HVRSS. Clinically stable patients who were well adapted to HMV were invited to participate in our study. Sampling and responder bias could potentially confound the results as those who responded to the survey may be different to the rest of the study population. Caution should be exercised in generalising the data.

The inclusion of a concomitant generic HRQoL instrument, such as the SF-36, would have allowed for comparison to other chronic disease groups. However, we felt that its inclusion may add unnecessary burden on the study participants in a cohort with high degrees of disability, and compromise the feasibility this pilot study.

Given the low prevalence of HMV, future studies could look into collaboration with other Asian centres to improve statistical power. HRQoL changes over time could be tracked using longitudinal data.

Conclusion

HMV patients have fairly good overall HRQoL and optimal medical care. Non-invasive ventilation was associated with better social relationship and social functioning. More could be done about psychosocial well-being to enhance HRQoL.

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