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RESEARCH PAPER

*The Norwegian version of the Severe Respiratory Insufficiency Questionnaire**

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The Norwegian version of the Severe Respiratory Insufficiency (SRI) Questionnaire

The aims of this study were to translate and adapt the Severe Respiratory Insufficiency (SRI) questionnaire into Norwegians and to test its reliability and validity.Data were collected from a cross-sectional survey and were linked to the Norwegian Registry of patients receiving long-term mechanical ventilation (LTMV). Of 193 potential participants, 127 responded to the SRI questionnaire. Reliability as measured with Cronbach's α varied between 0.68 and 0.88 for the subscales and was 0.94 for SRI-sum score. Construct validity was obtained with high correlations between subscales in SF-36 and SRI. The SRI questionnaire discriminated well between universally accepted clinical differences among categories of patients receiving LTMV by significant dissimilarities in SRI-sum score and SRI subscales. The Norwegian version of SRI has well-documented psychometric properties regarding reliability and validity. It might be used in clinical practice and in international studies for assessing health-related quality of life in patients receiving LTMV.

Key words: chronic respiratory failure (CRF), health-related quality of life (HRQOL), long-term mechanical ventilation (LTMV), the Severe Respiratory Insufficiency (SRI) questionnaire, validation study.

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*Translation, adaptation and validation of the SRI questionnaire: A cross-sectional survey including patients receiving long-term mechanical ventilation in Norway

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INTRODUCTION

Long-term mechanical ventilation (LTMV) is a well-established treatment for patients with hypercapnic chronic respiratory failure (HCRF) caused by various underlying disorders, such as chest wall deformities, neuromuscular disorders and obesity hypoventilation syndrome (OHS).[1-4] The total number of patients treated with LTMV in Europe has increased and will rise further with medical advances and the ageing of the population.[5] The treatment prevalence in Norway at the end of 2010 was 26.5/100 000.[6]

Patient-reported health-related quality of life (HRQOL) is an important instrument to understand and improve overall quality of life in patients with chronic diseases such as HCRF. During the last two decades, several generic and disease-specific questionnaires have been developed to assess HRQOL.[7] Most generic questionnaires are not specific to any particular disease and allow comparisons of HRQOL to be made between patients with different diseases. One of the most commonly used and well validated is the 36-item Short Form Health Survey (SF-36).[8] Condition- or disease-specific questionnaires measure how a specific disease affects HRQOL. In the fields of respiratory care, the disease-specific questionnaires 'The Chronic Respiratory Questionnaire' (CRQ) and 'The St George's Respiratory Questionnaire' (SGRQ) are both well validated for use in patients with chronic obstructive pulmonary disease (COPD).[9,10] Patients with CRF caused by other diseases might report some of the same respiratory complaints as COPD patients. However, they might suffer from a heavier burden of symptoms and other kinds of disease-related problems, especially in the advanced stages of disease. About one in five LTMV users in the Norwegian population has a neuromuscular condition,[6] and their specific problems and symptoms are poorly covered in questionnaires such as the SGRQ and CRQ. As a consequence, two questionnaires were especially developed to measure HRQOL in patients with CRF on LTMV treatment: the Severe Respiratory Insufficiency (SRI) Questionnaire[11] and the Maugeri Foundation Respiratory Failure (MFR-28) Questionnaire.[12] The SRI, originally developed in German, has proven more reliable and valid than the MFR-28 in this specific patient population,[13] and the translation processes, validations and clinical applications have been published for the Dutch, English and Spanish versions.[14,15]

The SRI measures HRQOL in patients receiving LTMV. A questionnaire developed and tested in one country cannot merely be translated and used as a new version in another country. QOL questionnaires measure subjective and cultural relations, so it is necessary to test a new version of the questionnaire psychometrically to the specific country. The validation process consists of a number of stages, in which the researcher looks for evidence that the instrument produces useful measurements that reflect the respondents' QOL.[7] Particularly, 'construct validity' is the degree to which an instrument measures the construct it is supposed to measure. One of the most common approaches is to relate a construct to practical criteria, to examine the scores on the instrument of interest and then compare them with scores on a similar/comparable instrument.[16] In clinical research, the sensitivity of a scale and its ability to detect individual differences in clinical variables are also important.[17]

The aims of this study were to translate and transculturally adapt the SRI Questionnaire into Norwegian, and to test its reliability, internal consistency and construct validity. The specific research questions were threefold: (i) Is the SRI Questionnaire positively correlated with the SF-36?; (ii) Does the SRI Questionnaire discriminate between universally accepted clinical differences among categories of patients receiving LTMV?; (iii) Do the most ventilator-dependent patients have a lower HRQOL than patients requiring fewer hours on a ventilator? SRI data were collected from a cross-sectional survey, including patients from three counties in Norway in 2008.

MATERIALS AND METHODS

Design and patients

This cross-sectional study was performed in 2008 in the western region of Norway. Informed consent was obtained from each participant prior to the study, and the study has been approved by the Regional Committee for Medical Research Ethics and by the Norwegian Data Inspectorate.

All patients older than 18 years in the Norwegian National Registry of LTMV who were resident in three counties were invited to participate in the study. Patients treated with non-invasive and invasive LTMV who showed mental clarity and were well oriented were included. The LTMV had to be established for at least 3 months. The SRI and SF-36 Questionnaires, an information letter, and a stamped return envelope were sent by mail to the 211 LTMV users in the registry who met the eligibility criteria. Returning the questionnaire was

considered to constitute the patient's consent to participate in the study. After 1 month, a reminder letter and copies of the questionnaires were sent to the non-responders. The register was cross-checked with the National Inhabitant Registry before the questionnaires were mailed to avoid sending them to individuals who had recently passed away.

The SRI Questionnaire

The SRI Questionnaire was developed following an open interview in which patients receiving LTMV had given their important subjective impressions of their actual quality of life. It contains 49 items based on social, psychological and physical health domains, and is divided into seven subscales. The SRI was validated in a multicentre study that included 226 patients. All items are rated on a five-point scale, from 'strongly agree' to 'strongly disagree'. The summary scale (SS) is obtained as summary of the seven subscales. High SS values (range 0–100) indicate a better HRQOL.[11]

Validation instrument

For validation purposes, the SF-36 was used as the objective gold standard for criterion validity, as in the original validation study of the SRI.[11] The SF-36 was originally developed based on the Medical Outcome Study[8] and has been translated into and validated in several languages, including Norwegian.[18]

Procedures for the translation and cultural adaptation of the SRI into Norwegian were as follows. The author of the SRI consented to the Norwegian translation. The accepted procedures for the translation and adaptation of QOL instruments were followed.[19,20] A professional translator and a physician specialist in pulmonary medicine, whose first language was German, translated the SRI into Norwegian. The translators worked separately and did not cooperate in this phase. Two professional translators performed the back-translation to German. The translation process revealed discrepancies in the translation of some of the items, and modifications to the wording were made. In particular, translation of the word 'Luftnot' (English, shortness of breath) produced different Norwegian words. Finally, the translators agreed on a Norwegian version, ready for pretesting.

Measuring feasibility and face validity

A pilot test was performed to measure the face validity and feasibility of the translated instrument. Members of the Norwegian special interest organization for LTMV users, 'Respira', were invited to act as the pilot test group. All of the six individuals in question had been receiving LTMV for at least 3 months. They were requested to complete the questionnaire and were then asked if the questionnaire was clear, easy to understand and covered topics of interest, and whether any items had been difficult to answer. They were also asked whether the questionnaire was relevant to their lives as LTMV users.

A group of health-care workers, physicians and nurses experienced in LTMV were asked whether the items were relevant for use in the LTMV population. The back-translated version of the questionnaire was also sent to the author of the original SRI, who commented on it in terms of the equivalence between the original and the back-translated versions.

Finally, a consensus group compared the translated version and the original for equivalence, face validity and feasibility. After its translation and pretesting in both the consensus and user groups, the Norwegian version of SRI was ready for psychometric testing.

Statistical analyses

Statistical analyses were performed by SPSS for windows version 18.0 (SPSS Inc., Chicago, IL, USA).[21] All statistical tests were two sided, and *P*-values below 0.05 were considered statistically significant. Data were described as percentages or means ± standard deviation. The chi-squared test was used to test for difference in percentages, whereas the two-sample *t*-test was used to test for difference in means.

The items in the SRI were recoded according to the guidelines for the original SRI Questionnaire. The total SS of the SRI is calculated by summing the subscale scores (SRI-RC, SRI-PF, SRI-AS, SRI-SR, SRI-AX, SRI-WB and SRI-SF). Missing items in the SRI and SF-36 were treated according to the accepted guidelines for these questionnaires, that is, the calculations were not performed if results were missing for one of the scales.[11] Internal consistency for each domain, subdomain and the SS for the SRI questionnaire was calculated using Cronbach's α.

Forced vital capacity (FVC) and forced expiratory volume in one second (FEV1) in per cent of the predicted value (FVC% pred and FEV1% pred) was calculated according to Langhammer *et al*.[22] Daytime arterial blood gas was taken prior to the initiation of mechanical ventilation and during spontaneous breathing in indoor air.

All scores in the SRI Questionnaire were correlated with all scores on the SF-36 using Spearman correlation coefficient. Analysis of variance (ANOVA) was further used to explore the differences in SRI scores between the four main diagnostic groups (i.e. neuromuscular disease (NMD), COPD, OHS, chest wall disease).

RESULTS

Initially, 211 subjects from the National Registry of LTMV patients met the inclusion criteria for the study. Four of the patients were excluded because of a primary diagnosis of obstructive sleep apnoea and therefore did not fulfil the inclusion criteria for the registry. Nine patients returned the questionnaire unanswered because they had stopped using the ventilator. One patient had died during the week that the questionnaire was sent. Two patients were unable to answer the questionnaire, as judged by their relatives, and two patients were impossible to locate. This reduced the number of potential responders to 193. After a reminder letter had been sent, 127 patients finally completed and returned the questionnaire, giving a response rate of 65.8%.

Clinical characteristics of the LTMV patients

The clinical and demographic characteristics of the LTMV patients are shown in Table 1. The group of patients with NMD was heterogeneous in terms of their diagnoses. It consisted of patients with acquired conditions (post-polio syndrome, $n = 16$; amyotrophic lateral sclerosis, $n = 5$; cervical spinal cord lesion, $n = 1$; multiple sclerosis, $n = 1$; brain damage, $n = 3$; central hypoventilation syndrome, $n = 2$; Cheyne-Stokes respiration, $n = 3$) and congenital conditions (spinal muscle atrophy, $n = 4$;

Table 1 Clinical and demographic characteristics of the LTMV patients

Variable	NMD	COPD†	OHS	Chest wall disease‡
Subjects (*n*, %)	54 (42.5)	26 (20.5)	37 (29.9)	9 (7.1)
Males (*n*, %)	23 (18.1)	16 (12.6)	23 (18.1)	6 (4.7)
Age, years	57.2 ± 17.8	67.7 ± 9.2	65.9 ± 12.2	51.6 ± 18.3
Years of LTMV	5.7 ± 4.5	2.6 ± 1.9	4.9 ± 3.0	7.1 ± 6.7
FVC % predicted	66.1 ± 29.3	58.3 ± 19.1	70.1 ± 17.3	42.2 ± 22.2
FVC, litre	2.3 ± 1.1	2.2 ± 0.9	2.8 ± 1.0	1.7 ± 1.3
FEV_1, litre	1.6 ± 0.9	1.1 ± 0.6	2.1 ± 1	1.2 ± 1.1
FEV_1 % predicted	58.9 ± 26.9	36.2 ± 18.9	63.0 ± 23.9	37.3 ± 18.5
FEV_1/FVC % predicted	93.7 ± 23.3	60.9 ± 18.8	88.7 ± 18.3	89.5 ± 23.6
PO_2, kPa daytime	9.8 ± 1.9	7.0 ± 2.1	8.0 ± 1.9	10.1 ± 2.9
PCO_2, kPa daytime	6.26 ± 1.4	7.73 ± 1.6	7.75 ± 3.0	7.80 ± 2.7
BMI, kg/m^2	27.9 ± 10.0	29.6 ± 8.9	40.5 ± 7.6	25 ± 7.0
Tracheotomy, *n*	10	0	0	0
LTMV h/day (*n*, %)				
5–8	29 (23.6)	8 (6.5)	17 (13.8)	4 (3.3)
8–12	15 (12.2)	13 (10.6)	14 (11.4)	4 (3.3)
12–24	8 (6.5)	5 (4)	5 (4)	1 (0.8)
Marital status (*n*, %)				
Married or cohabiting	27 (21.3)	18 (14.2)	20 (15.7)	5 (3.9)
Single	19 (15)	3 (2.4)	9 (7.1)	4 (3.1)
Divorced	3 (2.4)	2 (1.6)	4 (3.1)	
Widowed	6 (4.7)	3 (2.4)	4 (3.1)	

Data are presented as means ± SD, unless otherwise stated. † One of the patients in this group had severe bronchiectasis disease. ‡ Three of the patients in this group had other diseases. BMI, body mass index; COPD, chronic obstructive pulmonary disease; FEV_1, forced expiratory volume in one second; FVC, forced vital capacity; LTMV, long-term mechanical ventilation; NMD, neuromuscular disease; OHS, obesity hypoventilation syndrome; PCO_2, partial pressure of carbon dioxide; PO_2, partial pressure of oxygen.

Table 2 Differences in the demographic and clinical characteristics of the LTMV patients who answered the questionnaire and those who did not return the questionnaire

	Participant	Non-participant	*P*-value
Subjects (*n*, %)	127 (100)	66 (100)	
Males (*n*, %)	68 (53.5)	37 (56)	0.763
NMD (*n*, %)	54 (42.5)	26 (39.4)	0.759
COPD (*n*, %)	26 (20.5)	10 (15.2)	0.439
OHS (*n*, %)	38 (29.9)	22 (33.3)	0.627
Chest wall (*n*, %)	9 (7.1)	8 (12.1)	0.287
Age, years	61.5 ± 15.6	58 ± 21.27	0.250
Years of LTMV	4.92 ± 4.05	4.67 ± 3.26	0.674
BMI kg/m^2	32.8 ± 10.5	32.2 ± 12.7	0.798
PO_2, kPa daytime	8.6 ± 2.24	8.3 ± 2.29	0.52
PCO_2, kPa daytime	7.16 ± 2.4	7.16 ± 2.0	0.993
FVC % predicted	64.6 ± 23.6	53.8 ± 23.2	0.052
FEV_1 % predicted	54.3 ± 25.9	47.8 ± 22.9	0.275
FVC, litre	2.4 ± 1.0	1.8 ± 0.9	0.005
FEV_1, litre	1.62 ± 0.96	1.32 ± 0.7	0.043

Data are presented as means ± SD unless otherwise stated. BMI, body mass index; COPD, chronic obstructive pulmonary disease; FEV1, forced expiratory volume in one second; FVC, forced vital capacity; LTMV, long-term mechanical ventilation; NMD, neuromuscular disease; OHS, obesity hypoventilation syndrome; PCO_2, partial pressure of carbon dioxide; PO_2, partial pressure of oxygen.

Duchenne muscular dystrophy, $n = 2$; myotonic dystrophy, $n = 2$; other muscle atrophies, $n = 7$; limb-girdle dystrophy and neuropathies, $n = 2$; cerebral disease, $n = 2$; mitochondrial disease $n = 1$). The group of patients with COPD included one patient with severe bronchiectasis disease. The group of patients with chest wall diseases included three patients with miscellaneous diseases. All patients had severe hypercapnic CRF with $PCO_2 > 6$ kPa before the commencement of LTMV. The patients with chest wall diseases had spent the longest periods on LTMV (Table 1).

The demographic and clinical characteristics of the LTMV patients who answered the questionnaire are compared with those of the patients who did not return the questionnaire in Table 2. A statistically significant difference was only seen for FEV_1 and FVC.

Reliability

Cronbach's α for each domain of the SRI varied from 0.76 to 0.88 (Table 3). Because of the possible misinterpretation of item 15, Cronbach's α was measured also for the SRI-SF domain excluding item 15. This misinterpretation might be explained by a perceived difference in 'feeling bonded to' and 'feeling connected to' the patient's home. The Cronbach's α before and after exclusion of item 15 was 0.84 and 0.80, respectively.

Table 3 Internal consistency of the Norwegian version of SRI

Scale	Number of items	Cronbach's α
Respiratory complaints (RC)	8	0.81
Physical functioning (PF)	6	0.76
Attendant symptoms and sleep (AS)	7	0.68
Social relationships (SR)	6	0.82
Anxiety (AX)	5	0.81
Psychosocial well-being (WB)	9	0.88
Social functioning (SF)	8	0.79
Summary scale (SS)	49	0.94

SRI, Severe Respiratory Insufficiency.

Validity

The correlation matrix for SRI and SF-36 for our study population is shown in Table 4. Generally, the correlations were high when the subscales of the SRI and SF-36 referred to comparable aspects of HRQOL, and were lower when different topics were correlated. The highest correlations were found between SRI-PF and SF-36-PF ($r = 0.729$; $P < 0.001$) and between SRI-WB and SF-36 VT ($r = 0.72$; $P < 0.001$), and between SRI-WB and SF-36 MHC ($r = 0.714$; $P < 0.001$). The lowest correlation was between SRI-AS and SF-36-PF.

To examine whether SRI Questionnaire might discriminate between clinical differences among categories of patients receiving LTMV, we examined difference in SRI scores between NMD, COPD, OHS and chest wall diseases using ANOVA. A statistically significant overall difference was found for all SRI subscales, except for the domain of SRI-AS (Table 5).

DISCUSSION

The aim of this study was to translate a condition-specific questionnaire that measures HRQOL in patients receiving LTMV. The SRI Questionnaire was translated into Norwegian, and the scale was tested for its reliability and validity in a Norwegian patient population. In the process

Table 4 Correlation matrix for the SRI and the SF-36

SRI	SF-36									
	PF	RP	BP	GH	VT	SF	RE	MH	PHC	MHC
RC	**0.378**	**0.520**	**0.362**	**0.633**	**0.521**	**0.515**	**0.400**	**0.286**	**0.527**	**0.396**
PF	**0.729**	**0.661**	**0.246**	**0.524**	**0.345**	**0.398**	**0.430**	**0.270**	**0.608**	**0.290**
AS	0.172	**0.206**	**0.494**	**0.359**	**0.436**	**0.330**	**0.252**	**0.323**	**0.339**	**0.272**
SR	**0.272**	**0.430**	**0.481**	**0.475**	**0.579**	**0.664**	**0.418**	**0.523**	**0.465**	**0.582**
AX	**0.297**	**0.408**	**0.449**	**0.499**	**0.436**	**0.582**	**0.439**	**0.494**	**0.421**	**0.548**
WB	**0.281**	**0.480**	**0.543**	**0.629**	**0.720**	**0.695**	**0.580**	**0.637**	**0.430**	**0.714**
SF	**0.417**	**0.613**	**0.449**	**0.589**	**0.518**	**0.656**	**0.446**	**0.373**	**0.587**	**0.489**
SS	**0.452**	**0.617**	**0.578**	**0.702**	**0.645**	**0.736**	**0.560**	**0.537**	**0.622**	**0.614**

Significant correlations are shown in bold type; and summary scales for each questionnaire in grey. *Notes:* The SRI domains were respiratory complaints (RC), physical functioning (PF), attendant symptoms and sleep (AS), social relationships (SR), anxiety (AX), psychosocial well-being (WB), social functioning (SF), and summary scale (SS). The SF-36 domains were physical functioning (PF), role-physical (RP), body pain (BP), general health (GH), vitality (VT), social functioning (SF), role-emotional (RE), mental health (MH), physical health component (PHC), and mental health component (MHC). SF-36, 36-item Short Form Health Survey; SRI, Severe Respiratory Insufficiency.

Table 5 HRQOL according to the four groups of patients receiving LTMV

	Total $n = 123$ Mean (SD)	NMD $n = 52$ Mean (SD)	COPD[†] $n = 25$ Mean (SD)	Obesity $n = 37$ Mean (SD)	Chest wall[‡] $n = 9$ Mean (SD)	*P*
SRI						
SS	55.8 ± 18.4	61.0 ± 14.7	43.2 ± 19.0	58.4 ± 18.3	55.8 ± 18.4	0.001
PF	38.8 ± 24,7	35.5 ± 23.5	31.4 ± 23.2	47.6 ± 25.2	47.6 ± 25.2	0.048
RC	56.3 ± 22.1	60.3 ± 21.7	40.3 ± 18.7	61.4 ± 21.1	65.0 ± 22.1	0.001
AS	56.0 ± 20.2	60.5 ± 21.1	54.4 ± 21.1	52.8 ± 18.5	48.1 ± 16.7	0.169
SR	66.5 ± 24,0	72.7 ± 20.3	53.7 ± 27.2	67.8 ± 23.0	60.1 ± 26.7	0.009
AX	60.5 ± 27.5	67.4 ± 24.6	41.2 ± 26.3	66.4 ± 25.1	50.5 ± 31.7	0.001
WB	60.5 ± 23.3	68.1 ± 20.3	47.3 ± 24.5	59.1 ± 23.6	61.3 ± 20.9	0.003
SF	49.7 ± 23.4	55.1 ± 22.6	34.0 ± 22.0	53.6 ± 19.3	46.7 ± 23.4	0.001

[†] One of the patients in this group had severe bronchiectasis disease. [‡] Three of the patients in this group had other diseases. One-way ANOVA. Significance level 0.05. *Notes:* The Severe Respiratory Insufficiency (SRI) domains were respiratory complaints (RC), physical functioning (PF), attendant symptoms and sleep (AS), social relationships (SR), anxiety (AX), psychosocial well-being (WB), social functioning (SF), and summary scale (SS). HRQOL, health-related quality of life; LTMV, long-term mechanical ventilation.

of translating the SRI into Norwegian, general guidelines were followed[7,19] and no major problems were encountered. Consistent with previous studies, there were some items missing,[7] which might be explained by several factors, including the use of numerous items, the content of some items and the ambiguity in the answer alternatives.[23] For example, we found that some missing items were linked to a question about the influence on the patient's marriage, which lacked an alternative option for single patients.

Internal consistency measures the homogeneity of the items in a questionnaire. A Cronbach's α value above 0.70 is regarded as acceptable, a value above 0.80 as good and a value above 0.90 as excellent.[7] In the original

German version of the SRI, Cronbach's α ranged between 0.73 and 0.79 for three subscales, and between 0.80 and 0.89 for four subscales.[11] This indicates that the reliability of the present study was the same or even better than that of the German version of the SRI and similar to that in the English, Dutch and Spanish validation studies.[14,15] Cronbach's α increases as the number of items in the scale increases, which might explain the high Cronbach's α values for the sum scores.[7] For the remaining subscales of the SRI, Cronbach's α was good to excellent and consistent with those of previous studies,[14,15] indicating good item homogeneity in the SRI. However, a very high Cronbach's α might also indicate that several items in the questionnaire are approximately equivalent,[7] but this is not the occasion in this study.

Regarding our first research question, the correlation matrix of the SRI and SF-36 confirmed the same pattern as Windisch and colleagues,[11] who established strong associations between physical functions, well-being, vitality and social functioning. As expected, the strongest correlations were between subscales that focused on comparable aspects of HRQOL in patients receiving LTMV, and the weakest correlations were between the subscales that focused on different aspects of life as an example between respiratory complaints and mental health.

A correlation coefficient between 0.20 and 0.80 is regarded as acceptable, but correlation coefficients higher than 0.70 between the instruments might indicate that they are measuring the same construct.[7] In both the present and previous studies, the correlation coefficient was higher than 0.70 for the domain 'physical functions and vitality', indicating that they were measuring the same subdomain. Previous validation studies found the lowest correlation between the subdomain 'attendant symptoms and sleep' in the SRI and the domain 'role-emotional' in the SF-36.[11,14] This was expected because the SF-36 was not designed to measure sleep disturbances or respiratory complaints,[24] which are frequently reported in patients with CRF.

Construct validity is one of the most important characteristics of a questionnaire and refers to the degree to which it actually measures the construct it is meant to measure. Construct validity can be established by several methods. One approach is the 'known group technique', which tests the discriminatory ability of an instrument by administering the questionnaire to groups expected to differ in some known characteristics.[7] Concerning our second research question, the results of the present study confirm the findings of previous validation studies, indicating that the SRI can discriminate between different diagnostic groups of patients.[11,14,15] Consistent with the findings of previous studies, the COPD patients had the lowest SRI-SS. They have more respiratory constraints than the other groups of patients,[3,11,14,15] and the association between respiratory complaints and HRQOL was highest in COPD patients, as shown in another study,[25] on both the physiological component scale and the mental component scale. The higher levels of anxiety and depression in COPD patients compared with other patients are also consistent with the results of other validation studies,[11,14,15] and the SRI total score was strongly associated with anxiety and depression, as assessed with the Hospital Anxiety and Depression Scale.[13] A review of previous studies has shown contradictory results in patients after they commenced LTMV.[26] Some studies have found significant improvements in HRQOL after the initiation of LTMV.[27–30] In two of these studies, the improvement in HRQOL seemed more marked in patients with higher body mass indices (BMIs), those with no obstructive sleep apnoea syndrome or OHS and those traditionally known as 'blue bloaters'.[29,30] The COPD patients in the present study also had high BMIs which might represent a subgroup of COPD patients with concomitant OHS or obstructive sleep apnoea syndrome receiving LTMV. Until recently, randomized controlled trials have demonstrated no significant improvements in HRQOL in COPD after the commencement of LTMV.[4,31–36] However, these studies had two important limitations. First, they did not use questionnaires specific for patients receiving LTMV. Second, these studies used low-pressure ventilator settings.[4,31–36] A new high-intensity pressure strategy for non-invasive ventilation, aimed at maximal improvement of the blood gas values, has been evaluated in some studies, and assessments with the SRI have shown improvements in HRQOL.[3,37,38]

Concerning our third research question, we found that the most ventilator-dependent patients had lower HRQOLs than patients who spent fewer hours on ventilation. These results are consistent with the findings of previous studies of patients receiving LTMV.[11,14,15]

A low response rate is common in survey studies and might result in non-response bias.[7] The response rate in the present study was 65.8%, and the responders and non-responders were similar with regard to their age, sex, diagnosis and period of requiring LTMV, which might indicate that ours was a representative sample.[7,23]

However, those who did not return the questionnaire had lower scores on the lung function test than those who returned the questionnaire. A reasonable interpretation of this difference is that the non-responders suffered more severe disease than the responders did. Other studies have confirmed the tendency for patients with more advanced disease to fail to complete questionnaires.[39] Mailing questionnaires might be a less than optimal way to administer the questionnaires. However, the phenomenon of 'social desirability responding', or the tendency to idealize one's life, could be less pronounced when the questionnaires are mailed, thus circumventing meetings between the researcher and the study participants.[40]

Implications for nursing practice

Nurses have a central role in the care and monitoring for LTMV patients. The information in the SRI is crucial in planning the structure, performance and evaluation of patient care for LTMV patients. The use of SRI questionnaire will be an important tool in this effort and the subscales give an understanding of what HRQoL represents for this group, in a way which no other questionnaire does. The subscale, *Respiratory Complaints* (RC), includes; dyspnoea with or without physical activity, during speaking and meals. The RC subscale is crucial information for nursing care and intervention. The scale *Attendents Symptoms and Sleep* (AS), addresses the quality of sleep. This is measured by the patients reported waking up during the night, problems with falling asleep, general interruptions to the sleep cycle and also symptoms, such as daytime tiredness, dizziness and headaches.

The *Physical Function* (PF) subscale gives information which is important for the patient's self-care or need for support. Information regarding the patient's ability to execute daily activities such as getting clothed, doing housework, shopping and leisure time, is significant for the nursing care performance and follow-up.

The subscale *Anxiety* reflects the patient's concerns and fears of breathlessness. It also includes patient avoidance of situations which could escalate or induce breathlessness or embarrass the patient. Awareness of the patient's anxiety is required to perform the necessary interventions in care. The *Social function* scale gives information about the patient's ability to take part in social activities. The subscale includes factors such as patient capability of going out for the evening, having visitors, and impact of the disease on the patient's friends and family.

The *Well-Being* scale in SRI consists of several global questions of how the patients in general feel about life, their expectations for the future and their reactions to the limitations of their disease. Nurse staff has an impotent role in improving the patient's HRQoL, and the SRI questionnaire is an important instrument in the care of patients receiving LTMV.

Conclusion and suggestions for further research

Weighing the gains made in HRQoL by prolonging treatment against the potential disadvantages of the same treatment is challenging and complex. However, the Norwegian version of the SRI qualifies for use as a valuable research tool in assessing HRQOL in patients receiving LTMV. Longitudinal and follow-up studies are recommended to determine the responsiveness of the Norwegian version of the SRI and to identify the changes in HRQOL over time in different groups of patients with different diagnoses receiving LTMV. It should also be possible to examine how demographic and clinical variables act as predictors of HRQOL.

Our study demonstrates that the Norwegian versions of SRI shows good levels of internal consistency, and face-, criterion- and construct validities. The translation and cross-cultural adaptation of this instrument allow its application to clinical practice and research within Norway, and to comparative international studies that assess HRQOL in patients receiving LTMV.

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