Quality of life of patients treated by home mechanical ventilation due to restrictive ventilatory disorders

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The quality of life of patients with hypoventilation and home mechanical ventilation (HMV) has not been well described. Modern quality of life assessment techniques were therefore introduced in a cross-sectional study of patients treated with HMV. The aim was to study various aspects of the patients' quality of life and relate them to the underlying diseases, blood gases and the type of ventilatory connection. The study comprised 39 patients, most of them ventilated only during the night (n = 35). Nasal ventilation predominated (n = 29). Patients treated with HMV reported satisfactory levels of both psychosocial functioning and mental well-being that compared well with a general population group. Their quality of sleep was generally good. The quality of life measures were mainly influenced by the patients' underlying disease. Patients with scoliosis expressed in almost all instances the best quality of life. The quality of life of patients with ventilation by tracheostomy was reported to be at least as good as that of patients with nasal ventilation. The global quality of life estimation was mainly determined by the mental state of the patients and their sleep quality and only to a minor extent by physical handicaps. In conclusion, the patients treated with HMV reported good psychosocial functioning and mental well-being, in spite of severe physical limitations and dependence on regular nocturnal ventilation.

Introduction

Home mechanical ventilation (HMV) is an effective way of treating hypoventilation due to scoliosis and neuromuscular disorders. Recently performed studies report symptom relief (1,2), improved blood gases (1–3) and increased vital capacity (1) and exercise tolerance (4). There are also indications of improved survival after start of HMV (5,6). During the past few years HMV has been more available and widespread due to the non-invasive methods for assisted ventilation (3,4,7,8). However, the quality of life of these patients has not been well described. Casuistic data suggest negative impacts on the patients' everyday life counteracting the ventilatory improvement achieved by HMV.

Techniques for assessing health status or health-related quality of life (9–11) have been well established during the past decade and have proven to be valid for Swedish conditions (12). The aim of this cross-sectional investigation was to study the quality of life of patients with HMV using these techniques and to relate the quality of life to the underlying disorder, the type of ventilatory connection and to blood gases.

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Table 1 Mean SIP, MAACL and HAD scores and mean global quality of life rating in 39 patients with home mechanical ventilation and in reference populations

<table>
<thead>
<tr>
<th></th>
<th>All patients</th>
<th>Scoliosis (n=13)</th>
<th>Post-polio (n=11)</th>
<th>Neuro-muscular (n=10)</th>
<th>Healed tbc (n=5)</th>
<th>Reference populations</th>
</tr>
</thead>
<tbody>
<tr>
<td>SIP total index</td>
<td>11.3</td>
<td>8.1</td>
<td>11.1</td>
<td>14.1</td>
<td>14.2</td>
<td>5.2*</td>
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<td>SIP physical index</td>
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<td>6.8</td>
<td>14.6</td>
<td>19.4</td>
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<tr>
<td>ambulation</td>
<td>17.7</td>
<td>13.1</td>
<td>18.5</td>
<td>23.1</td>
<td>16.8</td>
<td>4.7</td>
</tr>
<tr>
<td>body care/movement</td>
<td>13.4</td>
<td>2.1</td>
<td>17.2</td>
<td>28.0</td>
<td>5.1</td>
<td>2.8</td>
</tr>
<tr>
<td>mobility</td>
<td>7.2</td>
<td>5.1</td>
<td>8.1</td>
<td>7.2</td>
<td>10.8</td>
<td>2.5</td>
</tr>
<tr>
<td>SIP psychosocial index</td>
<td>3.5</td>
<td>1.5</td>
<td>1.4</td>
<td>8.4</td>
<td>3.8</td>
<td>5.1</td>
</tr>
<tr>
<td>emotional behaviour</td>
<td>3.8</td>
<td>1.8</td>
<td>2.1</td>
<td>8.0</td>
<td>4.6</td>
<td>7.9</td>
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<td>social interaction</td>
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<td>7.8</td>
<td>8.7</td>
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<td>alertness behaviour</td>
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<td>0</td>
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<td>communication</td>
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<td>1.9</td>
<td>14.6</td>
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<td>1.4</td>
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<td>SIP independent scales</td>
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<tr>
<td>sleep/rest</td>
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<td>8.6</td>
<td>10.6</td>
<td>11.4</td>
<td>10.3</td>
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<td>19.4</td>
<td>14.1</td>
<td>27.9</td>
<td>4.1</td>
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<td>60.2</td>
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<td>recreation/postimes</td>
<td>16.6</td>
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<td>14.4</td>
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<td>eating</td>
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<td>3.5</td>
<td>3.3</td>
<td>3.6</td>
<td>3.4*</td>
</tr>
<tr>
<td>MACL activation/deactivation</td>
<td>3.4</td>
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<td>3.3</td>
<td>3.4</td>
<td>3.4</td>
<td>3.4</td>
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<tr>
<td>MACL calmness/tension</td>
<td>3.4</td>
<td>3.4</td>
<td>3.4</td>
<td>3.4</td>
<td>3.5</td>
<td>3.2</td>
</tr>
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<td>2.1</td>
<td>3.1</td>
<td>3.5</td>
<td>2.3</td>
<td>4.4†</td>
</tr>
<tr>
<td>HAD depression</td>
<td>2.0</td>
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<td>1.8</td>
<td>1.8</td>
<td>4.0</td>
<td>3.3</td>
</tr>
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<td>Global QL rating</td>
<td>4.9</td>
<td>5.3</td>
<td>5.0</td>
<td>4.8</td>
<td>4.4</td>
<td>NA</td>
</tr>
</tbody>
</table>

*Mean SIP scores and MAACL scores for a population sample of 112 women (27), 39–73 years of age (mean 57 years).
†Mean HAD scores for another population sample of 89 healthy subjects (CP Engström, unpublished data), 39 women, 45–75 years of age (mean 63 years).
NA = not applicable.

ventilation was used by 35 patients. Daytime ventilation only was used by three and full-time ventilation by one patient. The methods used for assisted ventilation were positive pressure ventilation via nasal mask in 29 patients, ventilation via tracheostomy in six patients and via mouth piece in two patients. Negative pressure ventilation via cuirass respirator was used by two patients. The ventilators used for positive pressure ventilation were PLV 100 and Monnal D in most patients. The connection between the nasally ventilated patient and the ventilator was the Respironics Contura mask. Sixteen patients received supplementary oxygen treatment for variable periods of time during the day and night, combined with HMV at the follow-up.

STUDY PROTOCOL

The following variables were studied: General health status, using a broad spectrum of inventories for self-assessment of physical and psychosocial functioning, emotional state and mental health. Problems associated with assisted ventilation were recorded on a study-specific questionnaire. The battery of questionnaires was administered by a research nurse. Daytime and nocturnal blood gas values were measured.

The study was approved by the Göteborg University Medical Ethics Committee. Informed consent was obtained from all the participants.

GENERIC QUESTIONNAIRES

The Sickness Impact Profile (SIP) is a measure of the patient's overall health status (13). It comprises 136 items which are grouped into 12 categories (Table 1). These are used to describe dysfunction in a broad range of everyday life activities or behaviour. The result is given as a percentage of the total possible dysfunction. The SIP includes calculation of Physical and Psychosocial dimension scores and an overall aggregation of the 12 categories (Overall SIP score). Thus high scores indicate dysfunction, and a cut-off point > 10 was applied for severe dysfunction.

The Mood Adjective Check List (MAACL) was used to complement the SIP and measures emotional states and mental well-being (14). The short form of the
questionnaire contains 38 items categorized into three dimensions (Table 1). The patients indicate their current emotional state by marking a scale from one to four. High scores indicate a positive emotional state. The Hospital Anxiety and Depression scale (HAD) was used as a supplement to MACL to screen for psychiatric morbidity (15). HAD contains 14 items which can be categorized into two dimensions (Table 1). A scale from zero to three is used for each item. High scores indicate depression or anxiety.

The SIP and HAD were adapted to Swedish conditions (16,17).

STUDY-SPECIFIC QUESTIONNAIRE

A study-specific questionnaire on effects of HMV and 'on-treatment’ problems was developed and tested. It contains 57 items divided into sections on social life, problems with the ventilators or the ventilator connections and quality of sleep. The items on quality of sleep were adopted from a sleep questionnaire (18). A shortened sleep score with satisfactory reliability was formed from three items with high scores indicating disturbance. Several response formats were used; either four or five point scales to indicate degrees of severity or yes/no answers to specific problems. Breathlessness was evaluated using part of a prototype questionnaire to the broadly used Medical Research Council questionnaire (19). It provides five categories of severity from I to V. The global quality of life (QL) rating was adopted from the EORTC Core Quality of Life Questionnaire with a 1-to-7 response format from very poor to excellent (20).

BLOOD GAS VALUES

Daytime arterial blood gas measurements, including oxygen tension (\( PaO_2 \)), carbon dioxide tension (\( PaCO_2 \)) and standard bicarbonate were determined (Radiometer ABL 2) in samples of blood obtained from all patients in the sitting position. Nocturnal transcutaneous continuous recording of blood gas values was performed on 28 patients (27 with nasal ventilation).

Oxygen saturation (tc-SO\(_2\)) was measured with an Ohmeda Oximeter 3700 using a finger probe. Tc-\( PCO_2 \) was measured with a kapnometer TCM3, Radiometer (21,22). The mean tc-SO\(_2\) and the mean tc-\( PCO_2 \) were calculated (23).

STATISTICS

For comparison between groups Fisher’s permutation test was applied (24) and Pitman’s non-parametric permutation test was used for analysis of correlations (24). For comparison between diagnostic groups the Kruskal-Wallis’ non-parametric one-way analysis of variance was used (ANOVA) (25). The significance level was set at 5%, two-sided test.

To identify possible determinants of quality of life, a series of non-parametric bivariate (24) and partial correlations (26) were performed. Multiple regression then served to display the amount of explained variance by a linear combination of the most prominent determinants.

RESULTS

SOCIAL LIFE

Of all the patients with HMV, 44% were living alone and 36% were gainfully employed. Satisfaction with both relations to family or close relatives and dwelling was reported by 97%. Good or very good economy was reported by 90% of the patients whereas 79% reported satisfactory leisure-time. Total welfare was reported as satisfactory by 95% of the patients.

‘ON-TREATMENT’ PROBLEMS, SLEEP DISTURBANCES AND SATISFACTION WITH THE HMV THERAPY

Problems with lifting/moving the ventilator and with travelling were reported by 18/38 and 16/31 patients, respectively. Leakage through the nasal mask was reported by 6/27 patients and pressure by the mask by 6/29 patients. There were no current problems with infections in patients with ventilation by tracheostomy.

The mean time on ventilation was 7.7 h (SEM 0.6) daily. Regular sleep disturbances were experienced by 5/39 patients and 4/39 were almost never alert in the morning. Five out of 37 patients were almost always sleepy during the day. Regular use of hypnotics was reported by 2/38 patients.

In a 1-to-7 response format from very dissatisfied to very satisfied with the ventilator therapy, the mean value obtained was 6.1 (SEM = 0.18, range 3-7).

QUALITY OF LIFE OF PATIENTS WITH HMV COMPARED WITH POPULATION GROUPS

The Overall SIP showed greater dysfunction (\( P<0.001 \)) in the HMV group than in the reference group from the population (Table 1). The physical function was poor in HMV patients due to limitations in mobility and ADL. However, the SIP scores for psychosocial functioning did not differ significantly between patients with HMV and the reference group (27). Neither did the scores of MACL and HAD scale discriminate between patients and reference subjects (Table 1).
Table 2 Daytime arterial blood gases and type of ventilatory connection in the four diagnostic groups

<table>
<thead>
<tr>
<th></th>
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<th>Healed tbc (n = 5)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean PaO₂ (SEM) range</td>
<td>9.9 (0.25)</td>
<td>10.2 (0.29)</td>
<td>10.2 (0.51)</td>
<td>10.4 (0.36)</td>
<td>7.8 (0.75)</td>
</tr>
<tr>
<td>Mean PaCO₂* (SEM) range</td>
<td>6.8 (0.18)</td>
<td>7.0 (0.22)</td>
<td>6.2 (0.42)</td>
<td>6.6 (0.29)</td>
<td>7.7 (0.34)</td>
</tr>
<tr>
<td>Mean arterial standard bicarbonate† (SEM) range</td>
<td>27.7 (0.44)</td>
<td>28.5 (0.70)</td>
<td>26.4 (0.78)</td>
<td>26.6 (0.67)</td>
<td>30.3 (1.17)</td>
</tr>
<tr>
<td>Nasal mask/tracheostomy/other</td>
<td>29/6/4</td>
<td>9/3/1</td>
<td>8/2/1</td>
<td>8/1/1</td>
<td>4/0/1</td>
</tr>
</tbody>
</table>

*BkPa. †mmol L⁻¹.

BREATHLESSNESS RATING AND SLEEP SCORE IN RELATION TO OTHER QUALITY OF LIFE VARIABLES

High breathlessness rating correlated with high scores of the overall SIP (P < 0.05). However, no correlation was found with the Physical and Psychosocial indices of SIP. Breathlessness was also correlated with HAD anxiety and depression (P < 0.001 and 0.05, respectively). The sleep score was inversely correlated with the global QL rating (P < 0.01). Hence good sleep correlated with high global quality of life.

BLOOD GASES

The mean daytime PaO₂ was 9.9 kPa and PaCO₂ was elevated to 6.8 kPa (Table 2). The nocturnal tc-SO₂ was, on average, 94% (SEM=0.37, range 89–97) and the tc-PCO₂ was 7.0 kPa (SEM=0.31, range 4.4–10.3). Seven patients (five with scoliosis and two with healed tuberculosis) used oxygen during the daytime blood sampling and ten patients (six with scoliosis) used oxygen during the nocturnal recordings.

VENTILATORY CONNECTION AND BLOOD GASES

The mean daytime PaCO₂ and standard bicarbonate were lower in patients with ventilation by tracheostomy (5.4, SEM 0.53 and 25.0, SEM 1.07, respectively) than in those with nasal ventilation (7.1, SEM 0.15 and 28.4, SEM 0.45, respectively), (P < 0.01).

CORRELATIONS BETWEEN SELECTED BACKGROUND VARIABLES AND QUALITY OF LIFE

Univariate correlations were performed between age, diagnostic group, ventilatory connection and blood gases on the one hand and the Physical, Psychosocial and Overall SIP indices, the three MACL dimensions, the two HAD dimensions, the global QL rating, the breathlessness rating and the sleep score on the other. High age correlated with high breathlessness rating (P < 0.01).

The diagnostic groups had significantly different Physical and Psychosocial SIP indices (P < 0.05 and P < 0.01 respectively, ANOVA). Patients with scoliosis had the lowest SIP scores, i.e. the best functioning, in most indices (Table 1). Patients with scoliosis reported a lesser degree of Physical SIP dysfunction than all the other diagnostic groups (P < 0.01). Patients with various neuromuscular disorders had a greater degree of Physical and Psychosocial dysfunction than all the other diagnostic groups (P < 0.05 and 0.01 respectively). Patients ventilated by tracheostomy had a higher global QL rating (mean 6.5, SEM 0.22) than patients with nasal ventilation (mean 4.8, SEM 0.31), (P < 0.05). The MACL Activation score was also higher in patients with tracheostomy (P < 0.05).

Low standard bicarbonate values were significantly correlated with good mental well-being expressed as MACL Activation score, (P < 0.01), MACL Calmness score, (P < 0.05) and HAD depression score, (P < 0.05). Low PaCO₂ was correlated with MACL Activation score, (P < 0.05).

MULTIVARIATE ANALYSES OF MAJOR DETERMINANTS OF QUALITY OF LIFE VARIABLES

Multivariate analyses were performed to describe the ultimate strength of the relationship between background and quality of life variables. Standard bicarbonate was the single determinant of the MACL Activation score in a multivariate analysis and explained 28% of the variance. A multiple regression analysis was performed with the global QL rating as the dependent variable and all composite SIP, MACL and HAD variables and sleep score treated as background variables. The MACL Pleasantness score was a major determinant of the global QL rating. Only
the sleep score showed an independent contribution beyond the basic mood dimension. These two scores explained 52% of the global QL variance.

Discussion

In this study, we used modern techniques for the quality of life assessment to derive a detailed picture of the general health status in patients with HMV. No control group was investigated in this study but comparisons were performed with reference populations which were studied using the same questionnaires. The psychosocial functioning and mental state were good in our patients with HMV compared with the reference populations (27, CP Engström unpublished data), despite our patients' severe physical limitations and the nocturnal ventilation which in itself is a limitation of ordinary life. The quality of sleep was generally good in our patients, despite the regular nocturnal mechanical ventilation. This is noteworthy as the sleep quality was a major determinant of the global quality of life. The patients reported satisfaction with the therapy as a whole. The negative aspects reported were mainly practical; many ventilators seem too clumsy to move and transport.

The finding of good psychosocial functioning and mental state in this severely disabled group of patients may have several explanations. The patients constitute a selected group who showed motivation for the HMV therapy. Most of them were in advanced respiratory failure with symptoms of hypoventilation before HMV was initiated. It is reasonable to believe that the patients’ perception of well-being may be related to an improvement from a state of tiredness, sleep disturbances and fluid retention before the HMV was started. Their blood gas values also improved after start of HMV (J. Olofson, unpublished data). Furthermore, respiratory failure develops slowly and in comparison with an acute disorder a slowly progressive disease has a less negative influence on the subjects' perception of their functioning over time due to a common coping process, as shown in a study of patients with spinal injuries (17). Most of the patients had also been treated with nocturnal ventilation for a long time and were well adapted to the therapy. We do not believe, however, that the good quality of life reported by our patients using HMV was due to insensitive measuring instruments as these have been found to pick up effects on quality of life of other chronic diseases (27,28).

Our patients with HMV constitute a very heterogeneous group. It consists of patients with scoliosis or healed tuberculosis without paresis and patients with variable degrees of paresis due to post-polio syndrome or neuromuscular disorders such as Duchenne Dystrophy. This heterogeneity explains the differences between the diagnostic groups with regard to physical function and it may also explain the difference in psychosocial functioning (SIP). Patients with scoliosis reported the best physical function, by far, while patients with neuromuscular disorders were found to be the most impaired, both physically and psychosocially.

Standard bicarbonate and $\mathrm{PaCO_2}$ were the only blood gas values we considered in the correlation analyses since some patients had oxygen during the arterial blood sampling. The $\mathrm{PaO_2}$ is therefore difficult to evaluate. A relationship was found between good mental well-being and low standard bicarbonate or low daytime $\mathrm{PaCO_2}$ levels. It seems reasonable that optimal ventilation reflected by a low standard bicarbonate value should be related to better mental well-being.

In recent years ventilation by nasal mask has been a more commonly used and more often recommended method for the treatment with HMV than ventilation by tracheostomy and most patients in this study were ventilated nasally. In the present study, daytime blood gas values were better in patients ventilated by tracheostomy than in patients with nasal ventilation. The global quality of life rating was also better in these patients. The difference in global quality of life rating still existed after adjusting for age, sex, blood gases and diagnosis. None of the patients had changed over from tracheostomy to nasal ventilation because of trouble with the tracheostomy. The tracheostomized patients, however, had problems with infections in the stoma and fitting of the tube during the early period of therapy. The patients with tracheostomy had been treated for 146 months, on average, compared to 21 months for the nasally ventilated patients. Consequently, the tracheostomized patients have had a better opportunity to cope with their situation. A comparison of the quality of life between patients with different ventilatory connections may therefore be difficult to interpret due to patient selection. However, according to the present results, ventilation via tracheostomy may still be recommended in patients with nocturnal mechanical ventilation, as patients on this method reported a good quality of life and showed normal blood gases.

Breathlessness was a common symptom. The Breathlessness rating used in this study was correlated to other quality of life variables and seems to be an important measure of perceived symptoms. The global QL rating included in the study-specific questionnaire was correlated, as expected, with most function and mood variables. A similar global QL rating has frequently been used in quality of life studies as a target
variable. Most of the variance of the global QL rating was explained by one of the mood dimensions (MACL: Pleasantness). This is consistent with similar analyses in other groups of patients (17), supporting the notion that the global QL is mainly explained by mental well-being and to a much lesser extent by physical dysfunction. The quality of sleep expression (the 3-item sleep score) was the second most prominent determinant of the patients' global QL rating.

In summary, patients with home mechanical ventilation have good psychosocial functioning and mental well-being despite severe physical limitations and dependence on regular nocturnal assisted ventilation. Their sleep was generally reported as being good. A prospective study is needed and we plan to use similar questionnaires in a coming study of the quality of life of patients with HMV.

Acknowledgements

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References


19. College of general practitioners. Chronic bronchitis in Great Britain. BMJ 1961; (4); 973-979.


