Helserelatert livskvalitet hos pasienter med langtids mekanisk non-invasiv ventilasjon

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Masteroppgave i sykepleievitenskap

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Navn:	**Dato:**
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Tittel:
Artikkel: Associations between respiratory events and health related quality of life in patients treated with long-term non-invasive ventilation.
Refleksjonsoppgave: Sykepleie og langtids mekanisk non-invasiv ventilasjon – Faktorer som påvirker vellykket masketilpasning

Sammendrag: Masteroppgaven består av en artikkel og en refleksjonsoppgave.
Formål:
Artikkel: 1) Beskrive helserelatert livskvalitet (HRQOL) målt med Severe Respiratory Insufficiency Questionnaire (SRI) til pasienter med langtids non-invasiv ventilasjon. 2) Analysere assosiasjonen mellom uønskede respiratoriske hendelser og HRQOL. Refleksjonsoppgave: Belyse hvordan sykepleieren kan bidra til vellykket tilpasning av maske brukt ved langtids NIV.
Teoretisk forankring:
Artikkel: Langtids NIV øker eller bevarer HRQOL til pasienter med kronisk respirasjonssvikt, men det er fortsatt mangel på kunnskap om hvilke faktorer i behandlingen som påvirker HRQOL.
Refleksjonsoppgave: En teoretisk måte å systematisere kunnskap om sykepleie på, er å benytte Hesook Suzie Kim sine domener «klient», «klient-sykepleier», «praksis», og «miljø». Kunnskap om den komplekse behandlingen langtids NIV innbefatter alle domenene.
Metode:
Artikkel: Prospektiv tverrsnittstudie. Data ble innhentet i en et-års periode ved rutinemessig kontroll av NIV-behandling. Refleksjonsoppgaven: Bygger på kunnskap fra forskning, egne erfaringer og pasientens perspektiv.
Resultater:
Artikkel: Gjennomsnittlig global SRI-skår for HRQOL var 64.8 ± 14.5, med den høyeste skåren i SRI-Social Relationships (79.5 ± 15.6). Å være complient til behandlingen var assosiert med høyere skår i SRI-Attendant Symptoms and Sleep. Vi fant også at forekomst av uønskede respiratoriske hendelser er assosiert med flere lave subskårer i HRQOL. Refleksjonsoppgave: Sykepleiere kan gjennom sin kompetanse innen langtids NIV foreslå best mulig maske basert på individuelle behov. Gjennom utøvelse av faget kan sykepleieren bidra til å forebygge og behandle komplikasjoner knyttet til masken, inkludere pårørende, og styrke pasientens egenmestring gjennom interaksjon og opplæring.
Konklusjon:
Pasienter med langtids NIV har en akseptabel HRQOL, men uønskede respiratoriske hendelser kan forekomme under behandlingen, og er assosiert med en lavere skår i HRQOL. Ved å se langtids NIV i lys av Kims teoretiske rammeverk illustrerer det at sykepleiere i utøvelse av sitt fag bidrar til vellykket behandling og økt eller bevart HRQOL. Det fordrer at vi øker og synliggjør kunnskap om sykepleie og langtids NIV.

Nøkkelord: Helserelatert livskvalitet, non-invasiv ventilasjon, kronisk hyperkapnisk respirasjonssvikt, langtids mekanisk ventilasjon, lungesykepleie

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Name:	**Date:**
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Title:
Article: Associations between respiratory events and health related quality of life in patients treated with long-term non-invasive ventilation
Essay: Nursing and long-term non-invasive ventilation – Factors influencing successful mask fitting

Abstract: The master´s thesis consists of an article and an essay.
Purpose:
Article: 1) Describe health related quality of life (HRQOL) measured by the Severe Respiratory Insufficiency Questionnaire (SRI) in patients treated with long-term non-invasive ventilation (NIV). 2) Analyze the associations between HRQOL and undesired respiratory events. Essay: Reflect upon how the nurse can contribute in successful fitting of the mask.
Literature Review:
Article: Long-term NIV increases or maintain HRQOL in patients with chronic respiratory failure, but there is still a lack of knowledge of which factors that affects HRQOL.
Essay: A theoretical structure to systematize knowledge of nursing is to use Hesook Suzie Kim´s four domains; "client", "Client-Nurse", "Practice", and "Environment". Long-term NIV is a complex form of treatment that includes concepts from all four domains.
Method:
Article: Prospective cross-sectional study. Data collection was performed in 2013-2014 when patients were hospitalized for a regular follow-up. Essay: Based on research-literature, own experiences and the perspective of the patient.
Results:
Article: The mean global SRI-score was 64.8 ± 14.5 with the highest score in SRI-Social Relationships (79.5 ± 15.6). Compliance was associated with a higher score in SRI-Attendant Symptoms and Sleep. The findings indicate that frequent presence of undesired respiratory events, are associated with a lower score in several of the SRI subscores. Essay: Through knowledge in long-term NIV, nurses can suggest a proper mask based on the specific needs of the patient. Nursing practice can prevent and reduce complications associated with the mask, include next-of-kin, and strengthen the patient's self-mastery through interaction and education.
Conclusion:
Patients with long-term NIV have an acceptable HRQOL. However, undesired respiratory events during NIV are associated with lower HRQOL. Seeing long-term NIV in light of the framework of nursing by Kim, illustrates how nurses through nursing assessment contribute to successful initiation of the treatment, thus influencing the patients HRQOL. Therefore it is important to increase and highlight knowledge about nursing and long-term NIV.

Key words: Health related quality of life, Non-invasive ventilation, Chronic hypercapnic respiratory failure, Long term mechanical ventilation, respiratory nursing.

Forord

Jeg ønsker å takke min hovedveileder Tone Rustøen for å så små og store frø som jeg har kunnet kultivere videre. Min ferdige masteroppgave ville ikke blitt den samme uten dine gode råd og innspill. I tillegg ønsker jeg å takke biveileder Anners Lerdal og mine medstudenter for nyttige diskusjoner og refleksjoner under felles veiledninger.

Stor takk til mine medforfattere; Kollega Dr. Heidi Øksnes Markussen, Professor Ole Henning Skjønsberg og Professor Jean-Paul Janssens. Dere har øst av deres kunnskap både innen helserelatert livskvalitet, langtids NIV-behandling, statistikk og vitenskapelig fremstillinger. Tusen takk!

Avslutningsvis, ønsker jeg spesielt å takke min eksterne veileder, medforfatter og store kjærlighet Dr. Sigurd Aarrestad. Takk for at du inkluderte meg fra begynnelsen i prosjektet ditt, takk for bruk av data og ikke minst, takk for at du har hatt troen på meg og prosjektet mitt. Du har vært en viktig del av denne masteroppgaven, og du er en viktig del av mitt liv.

Anne Louise Kleiven

Oslo, 09.05.2021

Innholdsfortegnelse

MASTEROPPGAVENS DEL 1

ARTIKKEL

Associations between undesired respiratory events and health related quality of life in patients treated with long-term NIV

Essential title page information

Title: Associations between undesired respiratory events and health related quality of life in patients treated with long-term NIV

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Keywords:

Health related quality of life

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Abbreviations: NIV, Non-invasive ventilation; CHRF, chronic hypercapnic respiratory failure ; COPD, chronic obstructive pulmonary disease; HRQOL, health related quality of life; SRI, Severe Respiratory Insufficiency Questionnaire; SRI-SS, Summary Scale; SpO_2, pulse oximetry; SpO_2<90%10%, SpO_2 < 90 % in ≥ 10 % of total recording time; TRT, Total recording time; ODI, Oxygen desaturation index; $PtcCO_2$, transcutaneous CO_2; AHI, Apnea-Hypopnea index; PVA, patient ventilator asynchrony; BMI, body mass index

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Word count: Abstract: 244 Article: 3909

Abstract

Background: Non-invasive ventilation (NIV) can increase or maintain health related quality of life (HRQOL) for patients with chronic hypercapnic respiratory failure (CHRF), but there is a lack of knowledge about which factors influence HRQOL during long-term NIV.

Aims: 1) Describe HRQOL measured by the Severe Respiratory Insufficiency Questionnaire (SRI) in patients with CHRF treated with long-term NIV. 2) Analyze the associations between HRQOL and hypoxemia, hypercapnia and respiratory events such as apneas, hypopneas (AHI), and patient-ventilator asynchrony (PVA) occurring during long-term NIV.

Methods: We included 62 patients with long-term NIV scheduled for a follow up at Oslo University Hospital. Patients answered the SRI questionnaire and underwent daytime arterial blood gas, nocturnal pulse oximetry, sleep polygraphy and nocturnal transcutaneous CO_2.

Results: The mean global SRI for 62 patients was 64.8 ±14.5, with the highest score in SRI-Social Relationships (79.5±15.6). Compliant patients had a significant higher score in SRI-Attendant and Sleep. We found significant negative associations between nocturnal hypoxemia and SRI-Respiratory Complaint (r=-0.34, p=0.01) and SRI-Attendant Symptoms and Sleep (r=-0.34, p=0.01). Both daytime hypercapnia, nocturnal hypoventilation, and high AHI were associated with a lower score in SRI-Anxiety, while frequent PVA was associated with a lower score in SRI-Physical Function.

Conclusion: Patients with long-term NIV have an acceptable HRQOL. However, undesired respiratory events during NIV are associated with lower HRQOL in several of the SRI subscales. We suggest that interventional studies should be designed to confirm the possible relation between HRQOL and respiratory events during long-term NIV.

INTRODUCTION

Long term mechanical ventilation (LTMV) provided through a mask is an efficient treatment for patients with chronic hypercapnic respiratory failure (CHRF) due to neuromuscular diseases, restrictive thoracic disorders, obesity hypoventilation syndrome, central hypoventilation syndromes and chronic obstructive pulmonary disease (COPD) [1, 2]. The number of patients treated with LTMV is increasing [3], especially due to the large growth in the use of long-term non-invasive ventilation (NIV) [4]. In Norway the prevalence of LTMV increased from 20/100 000 in 2007 [5] to 51/100 000 in 2019 of whom 99 % were treated with long term NIV [6]. To put these figures in perspective, prevalence of use of LTMV in the same year, was 33/100 000 inhabitants in Sweden (97 % NIV) [7], and 39.5/100 000 inhabitants in Finland (98 % NIV) [8].

The goal of long-term NIV is to reduce mortality and morbidity, provide the possibility for severely impaired patients to continue a life at home, and increase or maintain health related quality of life (HRQOL) [9]. Assessing HRQOL can provide information about the range of problems that affect patients [10] and is associated with mortality [11, 12]. For patients with CHRF, curative treatment is rarely available, and the treatment itself can be experienced as a burden and cause side-effects, such as pressure sores or persistent leakage from the mask [13]. In these cases, HRQOL is an important and sometimes the principal outcome [10, 14-16]. When measuring HRQOL it is important to distinguish between generic and specific instruments [10]. Generic instruments are most useful in general surveys on health, for example when comparing HRQOL between patient-groups or between patient-groups and the general population [10]. A disease-specific instrument concentrates on the domains relevant to a certain condition and is therefore suitable for studies of specific therapeutic interventions [10, 17]. Commonly used instruments in studies of HRQOL in patients with CHRF include: the Maugeri Foundation Respiratory Failure Questionnaire, the Sickness Impact Profile, the Short-Form 36, the Chronic Respiratory Questionnaire, and the St. George Respiratory Questionnaire [18]. In recent years, a disease specific instrument, the Severe Respiratory Insufficiency Questionnaire (SRI), has been developed to better investigate how long-term NIV influences HRQOL [17, 19, 20].

Long-term NIV can improve HRQOL [13, 16, 21-23], but there is a lack of knowledge about which factors influence HRQOL during treatment. Markussen et al. [13] found an association between reduced HRQOL and both side effects of LTMV-treatment and reduced pulmonary

function, while satisfaction with the follow up from health care professionals was associated with better HRQOL. Dyspnea and hospital admission also seem to be associated with lower HRQOL [15]. Increased daytime bicarbonates can reflect nocturnal hypoventilation [1], and two studies have found an association between decreased physical function measured with the SRI and the level of bicarbonates [24, 25]. A German multicenter randomized controlled study proposed that the use of high ventilator pressure settings adjusted to normalize diurnal $PaCO_2$ could be an explanation for improved HRQOL in patients with COPD treated with long-term NIV when compared to previous studies [26].

Correction of diurnal hypercapnia, nocturnal hypoventilation [26-28], and improvement of oxygen saturation [2] are considered important in the follow up of CHRF-patients receiving long-term NIV. Reduction of undesired respiratory events, such as obstructive and central apneas, hypopneas, and patient ventilator asynchrony [2, 29-31] may also be of importance. Thus, there is an increasing awareness of the necessity of regular nocturnal monitoring and adjustment of the ventilator to reduce the frequency of undesired respiratory events and normalize the patients' blood gases [1, 31, 32]. Few studies have investigated the association between HRQOL and physiological parameters, such as daytime hypercapnia, nocturnal hypoventilation, apnea, hypopnea and patient ventilator asynchrony, in a large group of stable patients treated with long-term NIV.

The aims of this study were to 1) describe HRQOL measured by the SRI in a population of stable CHRF-patients treated with long-term NIV and 2) analyze the associations between HRQOL and persisting hypoxemia and hypercapnia, as well as respiratory events such as apneas, hypopneas, and frequent patient-ventilator asynchrony occurring during long-term NIV-treatment.

MATERIALS AND METHODS

Ethics

The study protocol was approved by the Norwegian Regional Committee for Medical and Health Research Ethics, NO = 2012/1142 and with Clinical trial registration NCT01845233.

The patients were informed that non-participation would not influence their follow up and that they could withdraw from the study at any time. Written informed consent was obtained from all patients.

Patients

We evaluated all CHRF-patients scheduled for a regular follow-up visit for long-term NIV at the Department of Pulmonary Medicine at Oslo University Hospital between April 2013 and May 2014, for inclusion. Patients treated for neuromuscular diseases, restrictive thoracic disorders, obesity hypoventilation syndrome, and central hypoventilation syndrome for a minimum of three months were eligible. Exclusion criteria were: age under 18 years, inability to co-operate, hospitalization due to an acute exacerbation, and modification of the treatment within the last three months.

Study design

We performed a prospective cross-sectional study. Data collection was performed when patients were hospitalized overnight for their follow-up visit. This study is part of a larger research project: "Monitoring long-term nocturnal non-invasive ventilation for chronic hypercapnic respiratory failure: What are the basic tools?" [1]

Measurements

Health Related Quality of life

HRQOL was measured with the SRI questionnaire. The SRI is a self-administered multidimensional tool which has shown very good psychometric properties [17, 19], good construct validity, and acceptable ceiling- and floor effects [24, 33]. It is translated into several languages, including Norwegian [34]. The SRI form consists of 49 items rated using a five-point Likert scale from "strongly agree" to "strongly disagree" and then grouped into seven subscales: "Respiratory Complaints", "Physical Functioning", "Attendant Symptoms and Sleep", "Social Relationships", "Anxiety", "Psychological Well-being", and "Social Functioning". The total score of the seven subscales is referred to as the Summary Scale (SRI-SS) and varies from 0-100, with a higher score indicating better HRQOL [19]. The respondents were asked to relate their answers to the week preceding their elective evaluation.

Respiratory events

Nocturnal hypoxemia, nocturnal hypoventilation, apnea/hypopnea, and patient ventilator asynchrony occurring during NIV were measured and evaluated as previously described [30, 32]. In short, nocturnal hypoxemia was evaluated with continuous overnight pulse oximetry (SpO_2) (Nonin Medical 2500), and we used three different cut of values for abnormal pulse oximetry: 1) $SpO_2 < 90$ % in $\geq$ 10 % of total recording time (SpO_2<90%10%) 2) Recurrent

SpO_2 oscillations, defined as $\geq$ 5 events/hour with a 3 % oxygen desaturation from baseline lasting 10-90 seconds (ODI3%), and 3) Recurrent SpO_2 oscillations, defined as $\geq$ 5 events/hour with a 4 % oxygen desaturation from baseline lasting 10-90 seconds (ODI4%) [30].

Nocturnal hypoventilation was evaluated with continuous transcutaneous CO_2 measurement ($PtcCO_2$) (TCM Tosca, Radiometer). We used three different definitions of nocturnal hypoventilation:

1) Hypoventilation according to the American Association of Sleep Medicine (AASM): an increase in $PtcCO_2$ to a value > 7.3 kPa for $\geq$ 10 min and /or an increase in $PtcCO_2$ > 1.3 kPa in comparison to an awake value, exceeding 6.7 kPa $\geq$ 10 min (AASM[1&2])
2) $PtcCO_2$ > 6.5 kPa $\geq$ 10 % of total recording time (PtcCO2>6.5$\geq$10%)
3) Peak $PtcCO_2$ > 6.5 kPa (Peak $PtcCO_2$ >6.5)

Daytime hypercapnia was evaluated by performing an arterial blood gas sampling from the radial artery (ABG) performed between 12:00 and 14:00, after the patient had been seated and breathing room air for 30 minutes. We considered $PaCO_2$ $\geq$ 6 kPa as abnormal, based on conventional criteria.

The occurrence of apnea, hypopnea and patient ventilator asynchrony was examined by performing a sleep polygraphy (Embletta Gold, Embla, USA) during NIV. The following signals, as recommended by the SomnoNIV group were used [35]: mask pressure, flow rate in the circuit measured by a pneumotachograph close to the mask, abdominal and thoracic movement with respiratory inductive plethysmography effort belts, body position, and pulse oximetry. The polygraphy was manually scored by visual inspection by two experienced physicians [29].

Criteria for apnea and hypopnea were adapted from the scoring rules of the AASM [36] and reported as Apnea-Hypopnea Index (AHI); numbers of events/hour of total recording time. We used two different cut off values for abnormal AHI: AHI $\geq$ 5 and AHI $\geq$ 10.

Criteria for patient ventilator asynchrony were adapted from previous studies [29], and reported as patient ventilator asynchrony index (PVAI): number of events with asynchrony/hour of total recording time and the percentage of total recording time with patient ventilator asynchrony (PVAT). We used three different definitions for abnormal

patient ventilator asynchrony: PVAI $\geq$ 5, PVAI $\geq$10, and PVAT $\geq$ 10 %.Compliance was evaluated by using data memorized by the ventilator software downloaded with Rescan 04.01.013 software for ResMed ventilators and with Encore Pro 2 2.1.6.0 software for Philips Respironics ventilators. Summary data covering the 3 months prior to the regular follow-up visit were collected. Patients were considered compliant if the 3 months synthesis report showed a mean use of their ventilator $\geq$ 4 hours/night

Statistical analyses

Demographic variables such as age, body mass index (BMI), duration of ventilator use, daytime PaO_2, daytime $PaCO_2$, FEV_1, FVC and FEV_1/FVC, and the SRI scores were inspected for normality by comparing mean, median and 5 % trimmed, then measuring if kurtosis was approximately 0 ± 2, and finally inspecting if the form of the Q-Q plot was s-shaped closely around the linear line. We reported the variables as mean ± standard deviation (SD) if normally distributed or otherwise as median and interquartile range. The same descriptive analysis was done with the SRI scales, both in the patient group as a whole, and after dividing the population into different groups based on gender, diagnoses, and BMI < / $\geq$ 30. Associations between SRI scales and respiratory variables such as % of TRT with nocturnal SpO_2< 90%10%, ODI3% and ODI4%, daytime $PaCO_2$ and nocturnal $PtcCO_2$, apneas, hypopneas, patient ventilator asynchrony, and usage for three months were tested for significant associations using the bivariate test Pearson`s *r*. We controlled for confounders such as age, gender and diagnoses.

Between-groups comparisons were performed by independent-samples t-tests. Results were considered significant when $p < 0.05$, 2-tailed. Effect size of mean differences was calculated by using Cohen`s *d* [37] and reported as small if the value was between 0.2-0.5, moderate if 0.5-0.8, and strong if above 0.8 [10]. Statistical analyzes were performed with SPSS (version 25, USA).

RESULTS

Patients

In total, 95 of the evaluated patients met the inclusion criteria and 67 were included (Figure 1). Four patients did not answer the SRI-questionnaire, while one answered only the first page, resulting in complete data from 62 patients (Figure 1). Neuromuscular diseases were the largest group of patients, followed by obesity hypoventilation syndrome, restrictive thoracic

disorders and central hypoventilation syndromes. Main characteristics of these patients are presented in Table 1.

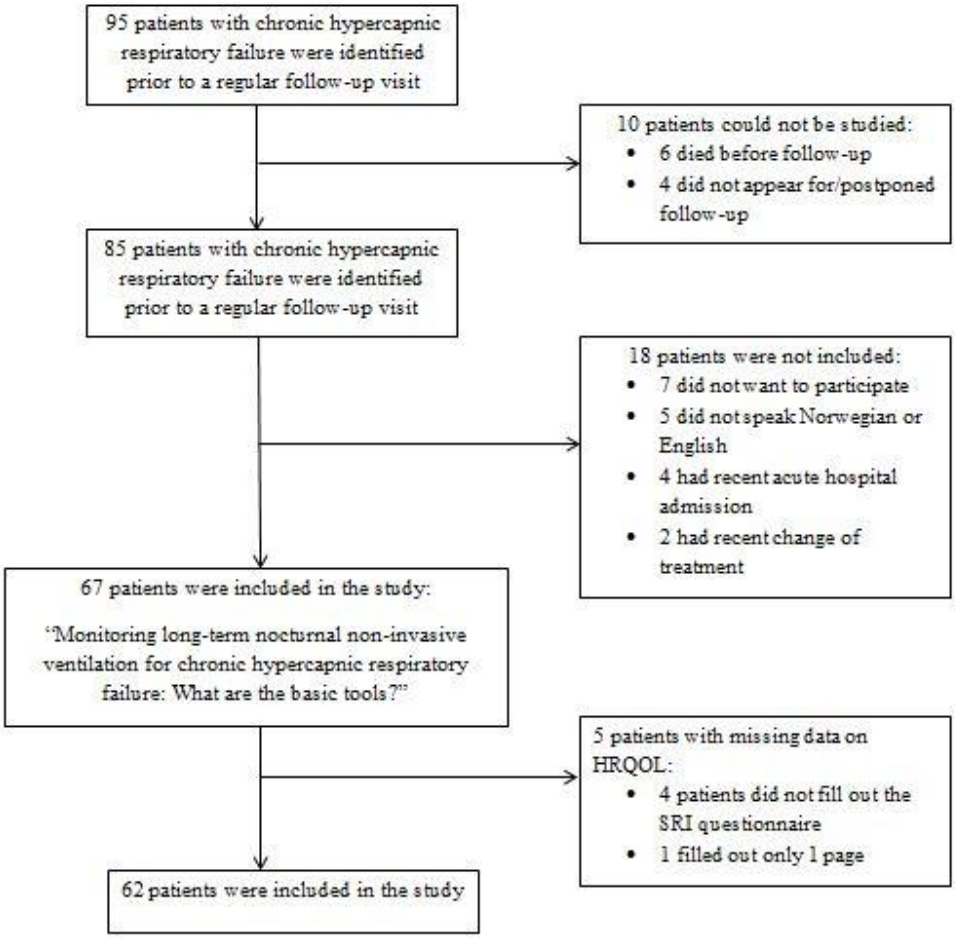

Fig.1. Flow chart showing numbers of patients and reasons for not participating

Health related quality of life measured with the Severe Respiratory Insufficiency Questionnaire

There were few missing items in the SRI questionnaire except for item 31, addressing the respondents' marital status, where 21 patients left the item unanswered. As outlined in Table 2, the mean SRI-SS for 62 patients was 64.8±14.5. Patients with central hypoventilation syndrome and restrictive thoracic disorders reported highest HRQOL scores, while patients with obesity hypoventilation syndrome reported the lowest scores. However, none of the differences reached statistical significance. The mean SRI-SS was in the upper half of the scale in all patient groups. Except for SRI "Physical Function", all of the SRI subscales were in the upper half of the scale, with the highest scores being in the SRI subscale "Social Relationships". Neither age nor duration of NIV-treatment was significantly associated with

any of the SRI subscales. There were no significant differences in SRI subscales related to gender or BMI < 30 / >30 (Table 2).

Compliance

Compliance data was analyzed for all patients. The median use was 8 hours (.8-9.3), and 85 % were considered compliant (mean use > 4 h/day) over a period of 3 months. There was a significant negative association between hours of use of NIV and the SRI subscale "Physical Function" (r=-0.28, p=0.03), suggesting that reduced physical capacity is significantly associated with increased use of the ventilator. When controlling for diagnoses, the result was no longer significant. When comparing patients with acceptable compliance (> 4 hours, n=53) with non-compliant patients (< 4 hours, n=9), we found a significant difference in the mean SRI subscale "Attendant and Sleep Symptoms" (67.8±17.2 vs. 52.8±22.9, p=0.02) indicating a higher symptom burden in the non-compliant group. The effect size / Cohen's d was 0.7, which is considered moderate.

Respiratory events and association with Health Related Quality of Life

Nocturnal hypoxemia

Nocturnal SpO_2 was successfully recorded in all patients, and median nocturnal SpO_2 was 93% (interquartile range: 91-95). We did not find any significant association between nocturnal SpO_2 and any of the SRI subscales. We found a significant negative association between the SRI subscale "Respiratory Complaints" and having a mean nocturnal SpO_2<90%10%, suggesting that hypoxemia is associated with a higher degree of respiratory symptoms (r=-0.34, p=0.01). We found a similar negative association between the SRI subscale "Attendant Symptoms and Sleep" and ODI4% (r=-0.34, p=0.01), implying that an increased ODI4% is associated with a worse "Attendant Symptoms and Sleep" score. Unexpectedly, when comparing patients with abnormal SpO2<90%10% with the group with normal SpO2<90%10%, we found a better HRQOL in the subscale for "Social Relationships" in the group with abnormal SpO2<90%10% (Table 3). This was also the case when we compared the group with abnormal vs., normal ODI3% (Table 3). However, in patients with ODI4%, there was a significantly lower score in "Attendant Symptoms and Sleep" scores in the group with abnormal ODI4%, vs. those with a normal ODI4 % (Table 3). The effect size was moderate (Cohen's d=0.7, 0.5 and 0.7) in all three findings.

Hypercapnia and Hypoventilation

Daytime $PaCO_2$ was available for all patients. Nocturnal $PtcCO_2$ was performed in all patients, but a technical error occurred in one patient.

The SRI subscale "Anxiety" was significantly lower (i.e. worse) in patients with daytime hypercapnia. This was also the case for nocturnal hypoventilation defined either by $AASM_{1\&2}$, or by Peak $PtcCO_2$ >6.5 (Table 4). Thus, there seems to be an association between both daytime hypercapnia and nocturnal hypoventilation, and increased perceived anxiety. Other correlations between hypercapnia and SRI scales did not reach statistical significance (Table 4).

The effect size was moderate (Cohen`s *d*=0.7, 0.6 and 0.5) in all the significant associations between CO_2 and anxiety.

Apnea and hypopnea

Polygraphy was available for all patients. We found no significant associations between SRI scales and the median value of AHI. However, patients with an abnormal AHI reported more anxiety than those with a normal AHI (Table 5). The effect size (Cohen's *d*=0.6), was moderate.

Patient ventilator asynchrony

Neither PVAT nor PVAI were significantly associated with SRI scales. However, we found lower scores for "Physical function" in patients with higher levels of patient-ventilator asynchrony (both PVAT and PVAI) (Table 5), suggesting a possible association between asynchrony and reduced physical capacity. The effect size (Cohen's *d*=0.5 and 0.6) was moderate in both findings.

DISCUSSION

In a group of stable patients treated with long-term NIV for restrictive pulmonary disorders, we assessed their HRQOL using the Severe Respiratory Insufficiency Questionnaire (SRI) and studied the association between HRQOL and respiratory events such as hypoxemia, daytime hypercapnia or nocturnal hypoventilation, apneas and hypopneas, patient-ventilator asynchrony and reduced compliance.

Our main findings were that both the SRI-SS and the SRI subscales scores were in the upper half of the scale (i.e. better values) in all patient groups, except for the SRI "Physical Function" subscale. Globally, SRI-SS were not significantly related to the physiological variables explored. However, we found significant associations between the subscale "Anxiety" and daytime hypercapnia, and/or nocturnal hypoventilation. We also found significant associations between patient-ventilator asynchrony and the "Physical function" subscale, and between nocturnal hypoxemia and "Social Relationships". Finally, all of the associations except for hypoxemia and SRI "Social Relationships" were negative, meaning that a higher number or severity of respiratory events was associated with a lower score in HRQOL.

The SRI-SS of 64.8±14.5 is in line with findings in previous studies. In a study of stable patients treated with LTMV for 6 years, by Markussen et al. [13], the SRI-SS was 64.8±16.8 with the highest score 79.1±19.5 being in the SRI "Social Relationships". Valko et al. [38] found a mean SRI-SS of 68.2±15.8 after 6 months of treatment, also with the highest score in SRI "Social Relationships". A review by MacIntyre et al. [22] concluded that HRQOL in patients with LTMV was generally described as good. Further, the score was more consistent in mental subscales, such as "Social Relationships" "Psychological Well-being" and "Social Functioning", compared to subscales exploring symptoms and function, such as "Respiratory Complaint", "Physical function", "Anxiety" and "Attendant Symptoms and Sleep". In studies with a majority of COPD patients included, the SRI-SS tends to be lower, indicating that COPD patients might experience a worse HRQOL than patients with restrictive respiratory disturbances [12, 15, 33]. COPD patients were not included in this study because in Norway at this time the national guideline based on the lack of evidence, did not recommend LTMV in COPD-patients [39], hence they represented a very small proportion of patients under LTMV-treatment at our center.

We did find significant associations between commonly used measurements for evaluating the efficacy of long-term NIV (nocturnal hypoxemia, daytime hypercapnia, nocturnal hypoventilation, AHI, assessment of patient ventilator asynchrony) and specific subscales of the SRI.

First, diurnal hypercapnia and nocturnal hypoventilation were associated with increased anxiety (SRI specific subscale), suggesting a negative impact on HRQOL. Hahn et al. [40] refers to the association that exists between the severity of symptoms and a worsening perception of HRQOL; hence when a patient in spite of long-term NIV still has daytime hypercapnia, we can expect that the symptoms will worsen HRQOL. It was interesting and important to identify that the SRI subscale "Anxiety" was negatively associated with measurements of nocturnal $PtcCO_2$, although many of the patients had a normal daytime $PaCO_2$. In a clinical setting where the evaluation is only based on daytime measurements, these patients might have been evaluated as sufficiently ventilated, despite a higher degree of anxiety. Anxiety is rarely listed as a primary symptom of hypoventilation. Symptoms of hypoventilation most often referred to, include dyspnea, fatigue, morning headache, daytime sleepiness, sleep disruption, and nocturnal dyspnea [1]. One could argue that dyspnea, can cause anxiety and, according to Feller-Kopman et.al. [41], anxiety is a clinical feature of slowly developing hypercapnia. Several studies have shown an improvement in the SRI subscale "Anxiety" after LTMV- treatment [25, 38, 42]. Our study suggests that patients treated with long-term NIV having less hypoxemia, hypercapnia and undesired respiratory events may experience less anxiety and we suggest investigating this in future studies.

Second, we found that the group with patient ventilator asynchrony (PVA) had significantly reduced scores in the SRI subscale "Physical Function". Physical function refers to the patient`s limitations in physical activities, such as climbing stairs, doing domestic work or dressing [19]. In studies reporting a high level of PVA, ineffective efforts were the most frequently observed type of asynchrony [29]. Atkeson et al. [43] also reported a high frequency of this respiratory event in patients with ALS. In a recent review by Baxter et al. [44] regarding ALS patients and optimization of NIV, regular monitoring was found to be of key importance and authors particularly recommended examining PVA. Also, the review warned against over-reliance on symptom reports, favoring adequate respiratory tests. Neuromuscular patients often have limitations in their physical capacities due to their muscle weakness, including the diaphragm [45]. Weak inspiratory muscles may cause ineffective

inspiratory efforts [1]. At least two hypotheses can be considered for this association: nocturnal PVA may have a negative impact on physical function through alterations of quality of sleep and increased work of breathing, or, conversely severely impaired physical function may favor unrewarded inspiratory efforts in spite of treatment with long-term NIV. This demands a more thorough evaluation of breathing patterns during sleep. Furthermore, the physiopathology of the link between PVA and decreased physical function may vary according to the underlying disorder.

Unexpectedly, nocturnal hypoxemia and desaturations were associated with higher (i.e. better) values in the "Social relationships" subscale. It is possible that perception of hypoxemia and desaturations was minimal or not perceived as clinically relevant. It is also interesting to note that scores for "Social relationships" were globally high, suggesting that in this group of patients and context, social interactions were preserved.

There are few studies on long-term NIV and HRQOL that have found an association between physiological measurements and patient-reported HRQOL. The general lack of association is often explained by the inadequacy of a physiological value, such as $PaCO_2$ or SpO_2, to reflect the perception and subjective state of the patient [23, 33, 40].

We did not find any significant associations between physiological measurements performed and the SRI-SS. This could question the clinical relevance of physiological end-points studied, as to their impact on HRQOL. Statistical significance does not imply clinical significance [10]. Even though several studies have shown an improvement in HRQOL measured with SRI after initiation of long-term NIV, the minimal clinically important difference (MCID) of the SRI questionnaire has to our knowledge not yet been defined [13]. Further insight has been provided by Raveling [46] in a study of COPD patients using a combination of clinical and patient reported anchors, estimating the MCID of the SRI-SS to be between 4.5 to 6.2 points. In our study we compared groups with undesired respiratory events with groups where these events were present to a lesser extent. Also, to our knowledge there are no studies which have investigated MCID in a similar patient group with a restrictive pulmonary function. We therefore used Cohen's effect size as a surrogate marker of meaningfulness of differences between groups: this is considered as an acceptable distribution-based evaluation of relevance, although not replacing a formally established MCID.

Strengths and Limitations

The respiratory measurements were prospectively collected, and of high quality. In addition, patients left few questions unanswered in the SRI questionnaire, leaving few missing items in our data. Our study has, however, some limitations. First of all, the study population is limited and heterogeneous, which may affect our results or lack of associations. However, some of the diseases that lead to CHRF are rare, and previous studies often provide similar sample sizes. Secondly, we did not include patients with COPD; providing LTMV in COPD at a large scale is not common practice in Norway, and thus patient selection represents local practice in home ventilation. This also decreases the heterogeneity of our population: patients we studied only had restrictive respiratory diseases. Finally, the study design cannot confirm or exclude causality between HRQOL and respiratory endpoints. Future studies should include several centers and be designed to include interventions targeting respiratory endpoints, such as apneas, hypopneas and patient ventilator asynchrony in order to measure the impact of these interventions on HRQOL.

Conclusion

In conclusion, our study shows that patients with long-term NIV have an acceptable HRQOL, as assessed by a disease specific HRQOL scale. Although undesired respiratory events under NIV did not affect global HRQOL scores, we found relevant negative associations between several of the SRI subscales and events such as hypoxemia, desaturations, daytime and/or nocturnal hypercapnia, AHI, and patient ventilator asynchrony. These associations suggest that prospective interventional studies should be designed to confirm the possible relation between HRQOL and respiratory events during long-term treatment with NIV.

Table 1

Main characteristics of the study population

	All patients	OHS	RTD	NMD	CHS
Patients	n=67	n=16	n=10	n=36	n=5
Male/female	35/32	8/8	3/7	20/16	4/1
Comorbidities: COPD/heart failure/renal failure/chronic opioid use	12/7/1/6	9/5/1/2	0	3/2/0/3	0/0/0/1
Interface; oro-nasal/nasal/nasal prongs	31/23/13				
FEV1(% predicted)	47.0±24.5	58.3±22.3	48.3±32.3	37.1±17.8	78.6±16.7
FVC(% predicted)	51.4±26.4	71.3±22.2	50.6±31.3	38.2±17.9	84.6±10.5
FEV_1/FVC (%)	75.0±13.6	63.5±11.9	76.8±11.5	79.6±12.7	74.6±9.2
Age (years)	57.7±19.2	65±12	45±25	59±19.2	49±14
BMI (kg/m^2)	28.1±7.7	36.7±5.2	26.5±8.1	24.8±5.7	28.0±5.8
LTMV duration, month, median (IQR)	54 (14–94)	35 (7-58)	80 (34-94)	57 (13-118)	60 (24-111)
Daytime PaO_2 (kPa)	9.4 (1.5)	8.4 (1.5)	9.5 (1.0)	9.6 (1.5)	9.9 (1.7)
Daytime $PaCO_2$ (kPa)	6.1±0.9	6.2±1.2	6.1±0.7	5.8±0.8	6.3±1.2

Values presented as mean ± SD, unless specified otherwise

Abbreviations: OHS: Obesity hypoventilation syndrome; RTD: Restrictive thoracic disorders; NMD: Neuromuscular diseases; CHS: Central hypoventilation syndrome; BMI: Body mass index; LTMV: Long Term Mechanical Ventilation; IQR: Interquartile Range; SpO_2: Oxygen saturation; $PaCO_2$: Partial pressure of carbon dioxide in arterial blood; kPa: Kilo Pascal; FEV: Forced Expiratory Volume; FVC: Forced Vital Capacity; COPD: Chronic Obstructive Pulmonary Disease

Table 2

Severe Respiratory Insufficiency Questionnaire scores in patient groups divided into gender, body mass index and diagnoses

SRI scales	All patients (n=62)	Male (n=35)	Female (n=32)	OHS (n=16)	RTD (n=10)	NMD (n=32)	CHS (n=4)	BMI<30 (n=39)	BMI>30 (n=23)
	Mean (SD)								
SRI-SS	64.8 (14.5)	63.2 (13.0)	66.6 (15.9)	62.8 (13.5)	68.6 (18.7)	63.2 (13.7)	76.6 (8.3)	65.2 (14.9)	64.3 (14.1)
Respiratory Complaints	63.0 (17.6)	62.0 (16.2)	64.0 (19.3)	63.4 (15.2)	72.9 (16.2)	57.9 (18.4)	76.6 (7.5)	62.5 (18.5)	63.8 (16.4)
Physical Function	46.4 (23.7)	42.1 (22.7)	51.0 (24.2)	37.0 (22.5)	55.4 (28.0)	46.4 (22.6)	61.5 (15.0)	48.6 (24.8)	42.6 (21.7)
Attendant Symptoms and Sleep	65.6 (19.0)	66.2 (17.9)	64.9 (20.4)	67.2 (18.6)	66.4 (17.0)	63.5 (20.8)	73.2 (11.1)	67.0 (17.4)	63.0 (21.4)
Social Relationships	79.6 (15.6)	79.5 (15.3)	79.8 (16.1)	80.6 (15.2)	78.3 (18.7)	78.6 (15.2)	87.5 (14.4)	77.4 (16.4)	83.4 (13.5)
Anxiety	64.9 (24.7)	62.5 (25.3)	67.5 (24.2)	63.4 (25.3)	72.5 (22.6)	60.9 (25.9)	80.0 (11.5)	65.8 (24.0)	63.5 (26.4)
Psychological Well-being	68.1 (17.7)	67.0 (16.5)	69.3 (19.1)	67.1 (20.3)	65.6 (24.8)	68.5 (14.7)	75.7 (12.5)	67.9 (16.9)	68.4 (19.5)
Social Function	66.3 (19.8)	63.0 (18.8)	69.8 (20.7)	60.2 (16.0)	69.1 (24.8)	66.6 (19.9)	81.6 (16.6)	66.9 (21.0)	65.2 (18.8)

Values presented as mean (± SD), unless specified otherwise

Abbreviations: N: numbers of patients; SRI: Severe Respiratory Insufficiency Questionnaire; SS: Summary Scale; N: Number of patients; NMD: Neuromuscular diseases; RTD: Restrictive thoracic disorders; CHS: Central hypoventilation syndrome; OHS: Obesity hypoventilation syndrome; BMI: Body Mass Index

Table 3

Comparison of Severe Respiratory Insufficiency Questionnaire scales and patients score based on the respiratory endpoints; Nocturnal hypoxemia

SRI scales	Respiratory endpoints					
	SpO_2 < 90 % in % of TRT		ODI 3 %		ODI 4 %	
	< 10%	≥ 10%	< 5	≥ 5	< 5	≥ 5
	Normal	Abnormal	Normal	Abnormal	Normal	Abnormal
Patients, numbers	n=43	n=19	n=29	n=33	n=45	n=17
	Mean (SD)					
SRI-SS	64.8 (15.7)	62.1 (14.3)	65.7 (15.5)	64.0 (13.7)	65.3 (15.3)	63.5 (12.3)
Respiratory Complaint	65.3 (16.0)	57.6 (20.3)	65.4 (14.7)	60.8 (19.9)	64.5 (16.1)	58.8 (21.2)
Physical Function	45.3 (25.1)	48.7 (20.6)	48.0 (24.0)	45.0 (23.7)	45.4 (25.3)	49.0 (19.3)
Attendant Symptom and Sleep	66.8 (19.0)	62.5 (18.7)	68.3 (19.4)	63.0 (18.3)	**68.8 (18.1)**	**56.1 (18.2)***
Social Relationships	**76.4 (16.1)**	**86.8 (11.6)***	**75.1 (16.7)**	**83.6 (13.5)***	78.5 (17.0)	82.6 (10.8)
Anxiety	67.1 (24.3)	60.0 (25.7)	70.0 (21.0)	60.5 (27.2)	67.2 (24.2)	58.8 (25.8)
Psychological Well-being	67.5 (19.7)	69.4 (12.4)	66.8 (21.1)	69.3 (14.4)	68.0 (19.3)	68.4 (13.2)
Social Function	64.8 (21.4)	69.8 (15.7)	66.6 (19.5)	66.0 (20.5)	64.6 (20.8)	70.8 (16.7)

Values presented as mean ± SD or numbers of patients.

SRI: Severe Respiratory Questionnaire; SpO_2: Oxygen saturation; TRT: Total recording time; ODI: Oxygen desaturation index; SD: Standard Deviation; SRI-SS: SRI-Summary Scale

*Significant differences $p < 0.05$, 2-tailed

Table 4

Comparison of Severe Respiratory Insufficiency Questionnaire scales and patients score based on the respiratory endpoints; daytime $PaCO_2$ and nocturnal $PtcCO_2$

SRI scales:	Respiratory endpoints:							
	Daytime $PaCO_2$:		Nocturnal $PtcCO_2$:					
	< 6 kPa	≥ 6 kPa	Hypoventilation AASM		$PtcCO_2$ > 6.5 kPa ≥10 % of TRT		Peak $PtcCO_2$ > 6.5 kPa	
	Normal	Abnormal	Normal	Abnormal	Normal	Abnormal	Normal	Abnormal
Patient, numbers	n=29	n=33	n=38[b]	n=23[b]	n=32[b]	n=29 [b]	n=19[b]	n=42[b]
	Mean (SD)							
SRI-SS	67.5 (13.6)	62.5 (15.0)	66.0 (14.2)	63.3 (15.2)	65.6 (14.7)	64.0 (14.4)	66.5 (14.9)	64.3 (14.5)
Respiratory Complaint	66.4 (17.1)	59.9 (17.8)	62.7 (18.4)	62.4 (16.3)	64.4 (19.3)	60.6 (15.3)	68.8 (18.5)	59.7 (16.5)
Physical Function	50.9 (25.0)	42.4 (22.0)	47.6 (22.3)	45.3 (26.4)	49.2 (22.8)	44.0 (24.8)	50.0 (25.2)	45.2 (23.2)
Attendant Symptom and Sleep	68.3 (17.2)	62.8 (20.1)	66.5 (19.4)	64.4 (18.1)	65.9 (20.6)	65.6 (17.1)	69.0 (16.6)	64.3 (19.7)
Social Relationships	79.0 (14.4)	80.2 (16.7)	79.8 (15.5)	79.5 (16.2)	78.0 (15.6)	81.6 (15.7)	76.6 (16.5)	81.1 (15.3)
Anxiety	**73.1 (19.8)**	**57.7 (26.6)***	**70.5 (21.8)**	**56.3 (27.5)***	70.2 (22.2)	59.7 (26.8)	**72.9 (15.4)**	**61.7 (27.6)***
Psychological Well-being	68.0 (19.5)	68.3 (16.3)	69.1 (17.6)	66.5 (18.6)	67.8 (18.1)	68.6 (17.9)	65.5 (21.2)	69.3 (16.4)
Social Function	67.1 (65.6)	65.6 (22.1)	65.3 (18.7)	68.5 (22.2)	64.0 (17.6)	69.4 (22.7)	62.8 (18.4)	68.2 (20.6)

Values presented as mean ± SD or numbers of patients

Abbreviations: SRI: Severe Respiratory Questionnaire; $PaCO_2$: Partial pressure of carbon dioxide in arterial blood; $PtcCO_2$: Partial pressure of carbon dioxide measured transcutaneous; kPa: Kilo Pascal; AASM: American Association of Sleep Medicine TRT: Total recording time; n:Numbers; SRI-SS: Summary Scale

*Significant differences $p < 0.05$, 2-tailed

[a] Variable number due to one respondent that only answered one page in the SRI Questionnaire

[b] Variable number due to a technical error in PtcCO2-measurement in one patient

Table 5

Comparison of Severe Respiratory Insufficiency Questionnaire scales and patients score based on the respiratory endpoints; Apnea Hypopnea Index, Patient Ventilator Asynchrony Index

SRI scales	Respiratory endpoints									
	AHI				PVAT		PVAI			
	< 5	≥ 5	< 10	≥ 10	< 10%	≥ 10%	<5	≥5	<10	≥10
	Normal	Abnormal	Normal	Abnormal	Normal	Abnormal	Normal	Abnormal	Normal	Abnormal
Patients, numbers	n=40	n=22	n=47	n=15	n=50	n=12	n=40	n=22	n=51	n=11
	Mean (SD)									
SRI-SS	66.1 (14.4)	62.1 (14.3)	64.8 (14.7)	64.5 (13.6)	64.7 (15.4)	65.6 (10.3)	66.0 (14.8)	62.7 (13.9)	65.2 (14.8)	63.2 (13.0)
Respiratory Complaint	63.5 (17.9)	61.9 (17.4)	63.6 (17.6)	61.0 (18.2)	63.1 (18.0)	62.2 (16.8)	64.3 (17.5)	60.5 (18.0)	64.0 (17.4)	58.0 (18.1)
Physical Function	49.0 (23.8)	41.7 (23.3)	46.1 (24.1)	47.2 (23.1)	**48.3 (25.6)**	**38.5 (10.5)***	49.5 (25.9)	40.7 (18.1)	**48.4 (25.1)**	**37.1 (12.1)***
Attendant Symptom and Sleep	65.5 (18.7)	65.3 (19.5)	65.8 (18.8)	64.0 (19.5)	64.2 (18.9)	70.5 (18.6)	65.8 (17.6)	64.7(21.2	64.6 (17.6)	69.2 (24.6)
Social Relationships	79.9 (16.7)	79.2 (13.6)	79.4 (16.4)	80.3 (13.0)	78.6 (16.4)	83.7 (11.3)	80.0 (15.9)	79.0 (15.3)	78.7 (16.4)	83.7 (10.3)
Anxiety	**70.3 (21.1)**	**55.2 (28.2)***	66.4 (23.8)	60.3 (27.7)	64.6 (24.9)	66.3 (25.1)	66.4 (23.6)	62.3 (27.0)	66.2 (23.2)	59.1 (31.5)
Psychological Well-being	68.1 (20.1)	68.2 (12.8)	67.3 (18.9)	70.7 (13.6)	68.0 (18.4)	68.4 (15.3)	69.0 (17.2)	66.6 (19.0)	67.7 (18.2)	70.1 (16.1)
Social Function	68.0 (18.4)	63.2 (22.3)	65.7 (19.4)	68.0 (21.9)	65.6 (21.6)	69.4 (9.9)	67.3 (21.0)	64.5 (18.1)	66.6 (20.6)	65.0 (16.5)

Values presented as mean ± SD or numbers of patients.

Abbreviations: AHI: Apnea Hypopnea Index; PVAT: patients ventilator asynchrony total recording time; PVAI: Patient Ventilator Asynchrony Index: SRI: Severe Respiratory Questionnaire; SD: Standard Deviation; SRI-SS: Summary Scale

*Significant differences $p < 0.05$

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[2] J. van der Geer, J.A.J. Hanraads, R.A. Lupton, 2018. The art of writing a scientific article. Heliyon.19, e00205. https://doi.org/10.1016/j.heliyon.2018.e00205.
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[3] W. Strunk Jr., E.B. White, The Elements of Style, fourth ed., Longman, New York, 2000.
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[4] G.R. Mettam, L.B. Adams, How to prepare an electronic version of your article, in: B.S. Jones, R.Z. Smith (Eds.), Introduction to the Electronic Age, E-Publishing Inc., New York, 2009, pp. 281–304.
Reference to a website:
[5] Cancer Research UK, Cancer statistics reports for the UK. http://www.cancerresearchuk.org/aboutcancer/statistics/cancerstatsreport/, 2003 (accessed 13 March 2003).
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MASTEROPPGAVENS DEL 2

Refleksjonsoppgave

Sykepleie og langtids mekanisk non-invasiv ventilasjon – Faktorer som påvirker vellykket masketilpasning

Ord: 7511

INNLEDNING

Bakgrunn

I min masteroppgave har jeg fokusert på langtids mekanisk ventilasjon (LTMV) til pasienter med kronisk hyperkapnisk respirasjonssvikt. Jeg har valgt å skrive en vitenskapelig artikkel med tittelen «Associations between respiratory events and health related quality of life in patients treated with long-term non-invasive ventilation». I artikkelen har jeg undersøkt assosiasjoner mellom helserelatert livskvalitet (HRQOL) til pasienter som behandles med maskebasert LTMV; non-invasiv ventilasjon (NIV), og uønskede respiratoriske hendelser til tross for LTMV behandling. I masteroppgavens andre del ønsker jeg å reflektere over hvordan sykepleieren kan bidra med masketilpasning, slik at LTMV-behandlingen blir best mulig for den enkelte pasient.

Flere studier har vist at langtids NIV bevarer eller øker pasientens HRQOL (Kleiven, 2020). Den viktigste faktoren for vellykket tilpasning av langtids NIV er at pasienten opplever redusert dyspne og forbedret gassutveksling (Carron et al., 2013). Utilstrekkelige masketilpasning, som fører til redusert komfort, redusert etterlevelse (complience), og redusert effektivitet av behandlingen, er identifisert som en av hovedårsakene til mislykket langtids NIV (Brill, Pickersgill, Moghal, Morrell, & Simonds, 2018; Hess, 2007). En av få studier som har sett på assosiasjonen mellom HRQOL og ubehag knyttet til masken, fant assosiasjoner mellom bivirkninger av LTMV-behandlingen, som sår på huden eller lekkasje fra masken, og en lavere skår i HRQOL (Markussen, Lehmann, Nilsen, & Natvig, 2018).

Hva er langtids mekanisk ventilasjon?

LTMV er en av de mest avanserte behandlingsformer som tilbys pasienter utenfor sykehus (Dybwik, 2011). Pasientene som får LTMV-behandling har utviklet kronisk hyperkapnisk respirasjonssvikt, som følge av nevromuskulære sykdommer, adipositas hypoventilasjon, brystveggslidelser, svikt i sentral respirasjonsregulering eller kronisk obstruktiv lungesykdom (KOLS) (Aarrestad, 2020). Respirasjonssvikt oppstår når gassutvekslingen er utilstrekkelig, enten ved lav oksygenmetning i blodet og/eller eliminasjon av karbondioksid (CO_2) fra venøst blod. Respirasjonssystemet består av to deler: lungen hvor gassutvekslingen foregår og pumpen som ventilerer lungen. Ved en hyperkapnisk respirasjonssvikt er det primært svikt i pumpen som ventilerer lungen, og som resulterer i utilstrekkelig gassutveksling (Aarrestad,

2020). LTMV kan defineres som mekanisk ventilasjon brukt over 4 timer daglig, i mer enn 6 uker, og som foregår utenfor spesialisthelsetjenesten (Aarrestad, Fondenes, & Fritzon, 2012). I følge Nasjonal faglig retningslinje for LTMV etableres behandlingen etter en vurdering av spesialisthelsetjenesten (Aarrestad et al., 2012). Etter utskrivning følges pasienten opp av spesialisthelsetjenesten, med kontroller fra 1-4 ganger per år (Aarrestad et al., 2012).

Teoretisk rammeverk for masteroppgaven

I følge Store norske leksikon kan refleksjon bety «å overveie eller tenke over noe» (Gundersen, 2005-2007). Alvorlig syke pasienter med avansert behandling, som for eksempel LTMV, ivaretas ofte av multidisiplinære team. Legen diagnostiserer og initierer behandling, fysioterapeuten gjør lungefysio-øvelser, ernæringsfysiologen følger opp næringsstatus og ergoterapeut skaffer til veie hjelpemidler. Det er ikke alltid like lett å skille ut hva som er sykepleierens ansvarsområde, ettersom vi ofte beveger oss inn i områdene til andre profesjoner. Sykepleieteoretiker og professor Hesook Suzie Kim har utviklet et teoretisk rammeverk for å systematisere kunnskap for å utvikle sykepleierfaget. Gjennom å dele sykepleien inn i ulike domener som: «klient», «klient-sykepleier», «praksis» og «omgivelser», ønsker hun å utfordre sykepleiere til en akademisk refleksjon over egen rolle (Kim, 2000). I masteroppgavens første del har jeg sett på HRQOL og hvordan pasienten håndterer livet med langtids-NIV. Selv om temaet i artikkelen, i følge Kim sitt rammeverk, befinner seg hovedsakelig innenfor «klient» domenet, beveger det seg også inn i de andre domenene. Å forberede pasienten på å komme tilbake til hjemmet med avansert medisinsk utstyr, som kanskje både ektefelle og hjemmesykepleie må kunne beherske, krever at LTMV-sykepleieren interagerer med andre aktører utenfor sykehuset. Dette refererer Kim til som «miljø»-domenet. I tillegg vil god opplæring og tiltak for å styrke pasientens egenmestring, fordre en gjensidig utveksling av erfaring og kunnskap, som beveger seg mer inn i domenet «Klient-sykepleier» (Kim, 2000). Avslutningsvis, vil økt eller bevart HRQOL forutsette at vi lykkes med langtids NIV-behandlingen, som igjen vil være avhengig av god masketilpasning.

Formålet med refleksjonsoppgaven

Det er flere faktorer som spiller inn for at behandling med langtids NIV skal bli vellykket og jeg vil synliggjøre området i behandlingen hvor sykepleieren gjennom sin praksis er en hovedbidragsyter. På sykehuset jeg arbeider har vi flere dyktige lungeleger med erfaring i å tilpasse pustemaskinen med riktige innstillinger, men valg og tilpasning av maske gjøres ofte av sykepleieren. Vi er i kontinuerlig kontakt med pasienten, både på dagen når vi tilpasser

utstyret, men også på natten, hvor lufttrykket fra maske og maskin fort kan bli en barriere for en god natts søvn. Sykepleiere møter ofte pasientene i sårbare og intime situasjoner og vi blir på godt og vondt, både en klagemur, en redningsbøye og en samtalepartner. Det kan virke som det er enklere å være ærlig overfor en sykepleier og innrømme at du er redd, umotivert eller kanskje ikke en gang har forstått hvorfor du bør bruke masken. Ettersom jeg har arbeidet med langtids NIV i flere år var det naturlig for meg å reflektere over hvordan sykepleieren kan bistå pasienten i å finne riktig maske. Dette arbeidet krever både evne til å planlegge sykepleie, gi omsorg, opparbeide seg ferdigheter og kunnskap, overvåkning, individualisere pleie og treffe en beslutning, som er typiske fenomener innenfor Kim sitt domene «Praksis» (Kim, 2000). I møte med LTMV-pasienten har sykepleieren en viktig og selvstendig rolle i det multidisiplinære teamet. Hensikten med oppgaven min er å reflektere over følgende:

«Hvordan bidrar sykepleieren i vellykket masketilpasning under etableringen av behandlingen og i oppfølgingen til pasienter med non-invasiv langtids mekanisk ventilasjon?»

I motsetning til akutt behandling, som ofte er tidsbegrenset, innebærer langtids NIV ofte en livslang behandling med maske. Jeg har valgt først å reflektere over fordeler og ulemper ved ulike typer masker, og når sykepleieren bør velge en maske fremfor en annen. Videre vil jeg reflektere over områder som sykepleiere må være bevisste på under etablering og oppfølging av langtids NIV; fare for dødrom-ventilasjon, klaustrofobi, lekkasje, sår, irriterte slimhinner, og øvre luftveis obstruksjoner. Dette er områder som kan skape en barriere for å lykkes med behandlingen, og som er faktorer hvor sykepleieren aktivt kan forebygge gjennom egne ferdigheter og kunnskap om masketilpasning. I tillegg vil jeg utdype hvordan sykepleieren ved å involvere pasienten, tilpasse viktig informasjon og utforme god opplæring, kan øke sannsynligheten for vellykket masketilpasning. Til slutt vil jeg reflektere over pårørendes rolle som viktig støttespillere i vellykket LTMV-behandling. Langtids NIV-behandling er kompleks og behandlingen strekker seg over alle domenene som, i følge Kim utgjør sykepleierens teoretiske rammeverk. Refleksjonsoppgaven kan bli et akademisk bidrag i å styrke sykepleierens kunnskap og praksis innen LTMV.

FREMGANGSMÅTE OG KUNNSKAPSKILDER

Refleksjonsoppgaven min er basert på kunnskap fra flere ulike kilder. I følge Helsebiblioteket innebærer kunnskapsbasert praksis at fagutøver bruker ulike kunnskapskilder, som forskningsbasert kunnskap, erfaringsbasert kunnskap og brukerkunnskap, når vi tar faglige avgjørelser i helsetjenesten (Helsebiblioteket, 2016) Refleksjonsoppgaven består av forskning innhentet gjennom et litteratursøk, egne erfaringer og en gjenfortelling av pasienters ønsker og behov formidlet til meg gjennom mitt virke som sykepleier.

Litteratur og forskning

Den forskningsbaserte kunnskapen i refleksjonsoppgaven ble innhentet gjennom et systematisk litteratursøk den 13. februar 2020 av en bibliotekar fra Medisinsk bibliotek ved Universitetet i Oslo. Vår problemstilling for søket var «Hvordan å ivareta pasienter som bruker langtids mekanisk ventilasjon». Vi søkte i et begrenset antall databaser, hvor de fleste var kilder for oppsummert forskning. I det videre arbeidet trakk jeg ut relevant litteratur, som omhandlet tilpasning av masker til langtids NIV og hvordan forebygge og behandle komplikasjoner av maskebruk. Jeg eksluderte studier som kun omhandlet akutt NIV-behandling og NIV til barn (<18 år). I tillegg inkluderte jeg artikler som omhandlet informasjon og opplæring, samt studier som undersøkte perspektivet til pårørende til LTMV-pasienter.

Forskningsbasert kunnskap er hentet fra de kliniske oppslagsverkene: UpToDate, BMJ Best Practice, Nursing Reference Center og VAR Healthcare. I tillegg har jeg inkludert en nasjonal retningslinje og en veileder, en klinisk retningslinje, samt systematiske oversiktsartikler og anbefalinger fra eksperter innen fagfeltet. Refleksjonsoppgaven er også basert på kunnskap fra fire enkeltstudier og fire kvalitative studier (Se vedlegg 1 for liste over inkludert litteratur)

Ettersom refleksjonsoppgaven ikke er en systematisk oversiktsstudie har jeg valgt ikke å vurdere aktuell litteratur opp mot systematiske sjekklister.

Egne erfaringer

Gjennom mine elleve år som sykepleier har jeg opplevd mange situasjoner med redde, kompetente, tøffe, umotiverte og motiverte LTMV-pasienter. Jeg har lykkes i å finne riktig maske og opplevd å endre masken til det bedre. Jeg har opplevd rennende neser, sår inntil beinet på neserygger, masker som har vært satt på opp ned eller stropper som er bak-frem. Jeg har måttet innrømme nederlag og innsett at planen min med å tilpasse en spesiell type maske

ikke lyktes. Refleksjonene over egen praksis kan bidra til å konkretisere den forskningsbaserte kunnskapen, gjøre masteroppgaven min mer praktisk rettet, og fungere som et nyttig verktøy for andre sykepleiere som arbeider med masketilpasning innen langtids NIV.

Pasientens stemme

I kunnskapsbasert praksis ønsker vi også å synliggjøre brukerens medvirkning (Helsebiblioteket, 2016). I min refleksjonsoppgave forsøker jeg å få frem LTMV-pasientens stemme gjennom kvalitative studier, og egne refleksjoner over pasientmøter.

OMRÅDER FOR REFLEKSJON

Hvordan lykkes med masketilpasning til pasienter med non-invasiv langtids mekanisk ventilasjon?

Den perfekte maske

Hva kjennetegner den perfekte maske og hvilke funksjoner bør den ha? Litteraturen foreslår følgende: minimal lekkasje, god stabilitet, lett, varer lenge, materialet endrer ikke form, ikke-allergisk material, gir liten luftmotstand, lite dødrom, lav kostnad, lette å produsere, tilgjengelig i flere størrelser, lett å ta av seg og er kompatibel med ulike respiratorer (Alqahtani & AlAhmari, 2018; Hess, 2012). Men hvor starter en uerfaren sykepleier? Hvilken maske bør du teste ut først? Jeg har presentert maskene nedenfor i en gjennomtenkt rekkefølge, med masken som vi ofte tester ut først og deretter i prioritert rekkefølge. I tillegg har vi i Norge en nasjonal innkjøpsordning, som gir føringer på valg av maske og produsent (Sykehusinnkjøp, 2021).

Nesemaske

En nesemaske kjennetegnes ved å omslutte nesen med trykkpunkter rett over neseroten, langs kinnet og rett over overleppen. Flere anbefaler å prøve ut nesemaske først (Aarrestad et al., 2012; Hess, 2007; Hill & Kramer, 2020). Dette skiller langtids NIV fra akutt NIV-behandling, hvor masker som dekker både munn og nese, representerer første valget (Hill & Kramer, 2020). Fordelene til en nesemaske er redusert risiko for aspirasjon, mindre klaustrofobi, redusert dødrom (Hess, 2012), bedre søvnkvalitet, behov for lavere trykk fra pustemaskinen, og mulighet til å spise (Alqahtani & AlAhmari, 2018; Schellhas et al., 2018). En nesemaske gjør det også lettere for pasienten å kommunisere med omverden, men erfaringsmessig kreves øvelse for å snakke mens maskinen er på. Å prøve ut nesemaske i en tidlig fase er svært viktig for pasienter som etter hvert vil kunne bli avhengig av kontinuerlig langtids NIV. Bruk av

nesemaske på dagtid vil lette deltagelse i hverdagen; både sosialt, men også for å være yrkesaktiv så lenge som mulig. I langtids NIV behandling til pasienter med KOLS med redusert alveolær ventilasjon, benyttes munn- og nesemasker i større grad enn nesemasker (Ergan et al., 2019). Utfordringen med nesemaske er ofte relatert til lekkasje ut av munnen, som både kan føre til ubehag for pasienten, men også redusere effekten av behandlingen (Fiorentino, Annunziata, Gaeta, Lanza, & Esquinas, 2018; Hess, 2012). Å kombinere nesemaske med en hakestropp kan redusere munnlekkasje (Hess, 2012; Hill & Kramer, 2018b, 2020). Nesemasken kan også medføre komplikasjoner i form av irritasjon i nesen og påfølgende rhinitt, og munntørrhet.

Nesemaske

Foto: Vy Rabben

Nesemaske i kombinasjon med hakestropp

Foto: Vy Rabben

Munn- og nesemaske

En munn- og nesemaske kjennetegnes ved å ha trykkpunktene over neseryggen, langs kinnene og mellom underleppen og haken, og tillater at du får luft både gjennom munn og nese. Den er velegnet når trykkene blir høye og kan føles mer behagelig hos pasienter med høy respirasjonsfrekvens og dyspne. Noen pasienter har vedvarende munnlekkasje, selv med hakestropp og vil derfor kunne tolerere en munn- og nesemaske bedre (Hill & Kramer, 2020).

Pasienter med bulbær amyotrofisk lateral sklerose (ALS) som strever med å holde munnen lukket, vil også kunne tolerere en munn- og nesemaske bedre (Dorst & Ludolph, 2019). Munn- og nesemaske gir god kontroll på munnlekkasje, men kan oppleves klaustrofobisk, gi økt dødrom, og gjøre det vanskelig å snakke, spise og drikke (Alqahtani & AlAhmari, 2018; Hess, 2012; Schellhas et al., 2018).

Munn- og nesemaske
Foto: Vy Rabben

Total ansiktsmaske

Total ansiktsmaske dekker hele ansiktet fra pannen til kjeven og flere studier viser redusert forekomst av sår ved bruk av denne masken (Alqahtani & AlAhmari, 2018; Hess, 2012; Hill & Kramer, 2020). En total ansiktsmaske kan også legge mer til rette for å snakke, enn en

tradisjonell munn- og nesemaske. Der i mot har den større risiko for dødrom-ventilasjon og irritasjon av øynene (Hess, 2012).

Total ansiktsmaske

Foto: Vy Rabben

Total ansiktsmaske og munn- og nesemaske øker risikoen for aspirasjon og i verste fall kvelning hvis pasienten kaster opp og mangler muskelkraft til å ta av seg masken (Hill & Kramer, 2020; Rolfe, 2019). Vi anbefaler derfor alltid at pasienter uten evne til å ta av seg masken selv, innvilges tilsyn på natt av kommunen.

Nesepropper og neseputer

Nesepropper og neseputer fører luften direkte inn i neseborene. De kan være velegnet hos pasienter med høy grad av klaustrofobi og i tillegg kan pasienten både spise, drikke, ivareta egen munnhygiene, og bruke briller samtidig som masken er på (Hess, 2007). Dette gjør at masken er velegnet til de som også bruker langtids NIV på dagtid. Ettersom luften kanaliseres

direkte inn i neseborene, kan ofte slimhinnene bli irriterte og føre til rhinitt (Hess, 2007). I tillegg kan også neseproppper føre til munnlekkasje, på linje med en nesemaske. Under behandling kan høye trykk føre til at proppene ikke sitter like godt og dermed øker risikoen for lekkasje (Fiorentino et al., 2018).

Neseproppper

Foto: Vy Rabben

Spesial tilpassede masker

En sjelden gang vil ingen av maskene være egnet og pasienten må få spesialtilpasset en egen maske. På vår avdeling har muskelsyke pasienter med for eksempel alvorlig benskjørhet, fått støpt egne masker, slik at risikoen for å skade når du strammer stroppene reduseres. Det finnes et fåtall firmaer som støper masker, og prosessen er ofte svært ressurskrevende.

Kunnskapsgrunnlaget for å velge en maske fremfor en annen er begrenset, så det endelige valget vil være basert på pasientens evne til å bruke masken og komfortnivået (Ergan et al., 2019). I kvalitative studier av LTMV-pasienter, fremhever pasientene selv hvor viktig det er å finne riktig maske for å oppleve god livskvalitet etter oppstart av langtids NIV-behandling (Brooks et al., 2004; Lindahl, Sandman, & Rasmussén, 2005).

Komplikasjoner av maskebehandling

Dødrom-ventilasjon

Dødrom-ventilasjon er en mulig årsak til ineffektiv langtids NIV-behandling (Hill & Kramer, 2018b). Fenomenet kan både hemme utåndingen av CO_2 og redusere avlastningen av pustemuskulatur. Dødrom-ventilasjon kan relateres både til valg av maske, respiratorkrets og respiratormodus (Carron et al., 2013). I opplæringen av nye sykepleiere fokuserer jeg på at det er viktig at pasienten puster frisk luft inn, men også at CO_2-rik luft må ut. Dette krever at enten masken har hull for ekspirasjonsluften, at slangen har en aktiv ventil eller at det er et eget løp for ekspirasjonsluft i kretsen (Carron et al., 2013). Utstyret brukt ved Langtids NIV skiller seg fra utstyr brukt ved akutt NIV-behandling. Blant annet ved å ha hull for utånding i masken, i stedet for aktiv ventil i respiratorkrets eller dobbelkrets. Det er derfor svært viktig at en LTMV-sykepleier har kompetanse i medisinsk teknisk utstyr og ikke manipulerer utstyret uten å kjenne til hvordan det påvirker dødrom-ventilasjonen.

Klaustrofobi

Redselen for å bli kvalt er ofte en naturlig reaksjon av å få en sykdom som rammer evnen til å puste. Når du da attpåtil får en maske på ansiktet, kan det oppleves som svært skremmende. I følge Carron (Carron et al., 2013) kan klaustrofobi være årsak til 5-20 % av mislykkede masketilpasninger. Klaustrofobi er en komplikasjon som ofte krever mye tålmodighet hos helsepersonell. Ofte kan en nesemaske eller nesepropper føles mindre klaustrofobisk, fremfor en maske som dekker både munn og nese (Carron et al., 2013). I følge Schub (Schub & Heering, 2018) kan også stramme hodestropper føre til klaustrofobi. God informasjon, som inkluderer en forklaring av hvordan sikkerhetsventilen på masken sørger for at du får frisk luft selv om maskinen skulle stoppe, er essensielt.

Trening på å ta av og på seg masken kan øke egen mestring av situasjonen. I møte med svært engstelige pasienter setter jeg meg på en stol ved sengen og kartlegger hva pasienten er redd for. Redselen bunner ofte i mangelfull kunnskap, men også i frykten for ikke å bli tatt på alvor. Etter at vi har snakket sammen setter vi sammen opp en plan for utprøving. Den første

gangen masken prøves, kan pasienten selv holde den foran ansiktet, uten at stroppene festes. Dette kan gi en følelse av å ha kontroll på situasjonen. Kan ikke pasienten holde masken selv, sier jeg at jeg holder, men at jeg tar av masken så fort han eller hun ber om det. Hvis jeg ser at pasienten slapper av, informerer jeg om at jeg går ut av rommet, etter at jeg har forsikret meg om at pasienten kan ta av seg masken selv og har mulighet til å varsle hvis de føler ubehag. Jeg lager alltid en avtale om at jeg kommer tilbake om for eksempel 5, 10 eller 15 minutter. Tid og tillit er nøkkelfaktorer for å lykkes. Avledende hjelpemidler, for eksempel å se på TV eller høre på musikk når pasienten tester pustemaskinen, kan også redusere følelsen av angst og klaustrofobi (Hill & Kramer, 2018a).

Flere anbefaler mindre doser av opioider eller benzodiazepiner hos pasienter med nevromuskulære sykdommer og brystveggslidelser som opplever panikkanfall, men det er viktig å være oppmerksom på faren for stigende CO_2 (Dorst & Ludolph, 2019; Hill & Kramer, 2018a). Beroligende medikamenter kan redusere evnen til å puste og under opptrapping er det derfor anbefalt at pasienten er under tilsyn. Erfaringsmessig er jeg positiv til en kombinasjon av lindrende medikamenter og NIV, spesielt hos pasienter med fremskredet muskelsykdom. Likevel opplever jeg at mange leger nøler med å introdusere denne type behandling og at mange pasienter nærmest opplever det som et nederlag. Det er viktig å understreke at lindrende medikamenter ikke erstatter et kompetent behandlingsteam. I tilvenningsfasen vil aldri medikamenter erstatte tilstedeværelse av en erfaren lege eller sykepleier, men det kan være et nyttig supplement (Dorst & Ludolph, 2019; Hill & Kramer, 2018a).

Lekkasje

Lekkasje kan defineres som forskjellen mellom volum av luft som leveres fra pustemaskinen og den faktiske luften som når pasientens lunger (Aarrestad, 2020). I LTMV benyttes ofte Bilevel Positive Airway Pressure (BPAP). BPAP forutsetter en viss intendert lekkasje gjennom hull og ventiler i masken for å unngå dødrom-ventilasjon. Til forskjell er ikke-intendert lekkasje, den varierende luftlekkasjen som oppstår mellom masken og ansiktet eller ut gjennom munnen når nesemaske er benyttet. Ikke-intendert lekkasje oppstår ofte fordi masketilpasningen ikke er grundig nok, for eksempel ved at sykepleieren velger en maske som er for stor (Gay, 2020). Videre kan lekkasje oppstå ved høye trykk, for stram maske, eller som en sekundær effekt av øvre luftveisobstruksjoner under søvn (Aarrestad, 2020).

Komplikasjoner av lekkasje

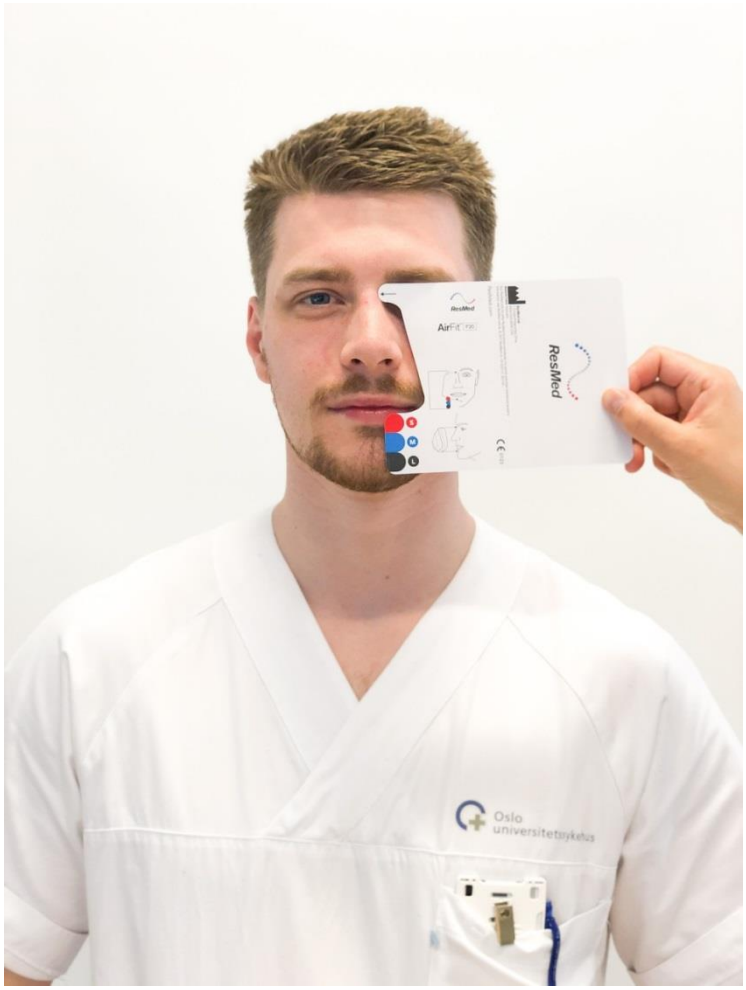
Mitt møte med pasienten «Amanda» illustrerer godt hvordan lekkasje kan medføre ytterligere plager i en allerede vanskelig livssituasjon. Amanda startet opp med langtids NIV ved vår avdeling og en kort stund etter utskrivning tok hennes ektefelle kontakt. Hun hadde fått plager med såre øyne og etterhvert konjunktivivitt. Under hjemmebesøket var det åpenbart at Amanda hadde fått tilpasset en altfor stor maske. Hun hadde en alvorlig form for bulbær ALS med redusert muskelkraft. Tapet av muskler i hals og kjeve førte til at munnen nærmest alltid var åpen, og hun hadde problemer med å holde hodet oppe. En nybegynner innen masketilpasning vil kanskje tenke at en stor maske kan holde haken oppe ved å ha endepunktet nedenfor haken. Hvis masken ikke er konstruert for å omslutte haken, vil en for stor maske i stedet føre til lekkasje, og i Amandas tilfelle, hadde lekkasjen ført til betennelse i øynene. Hun var rød og svært hoven og det rant væske fra begge øynene. Masken gled oppover ansiktet og det var nærmest umulig å få øyekontakt med henne. Jeg byttet ut masken med en tilsvarende i to størrelser mindre med ønsket effekt.

Irriterte øyne og konjunktivitt er kjente komplikasjoner (Boussaïd et al., 2016; Caple, 2017; Rolfe, 2019; Schub & Heering, 2018), men lekkasje kan også føre til en rekke andre utfordringer i langtids NIV-behandling. Det kan redusere pasientens evne til å trigge pustemaskinen (Boussaïd et al., 2016; Hess, 2012). Lekkasje kan også føre til tørre slimhinner i munn og nese, som igjen kan føre til økt sekret og rennende nese (Boussaïd et al., 2016; Hess, 2012; Schub & Heering, 2018).

Summen av problemene knyttet til ikke-intendert lekkasje fra masken kan føre til at hypoventilasjon vedvarer eller at pasienten får forringet livskvalitet, og i verste fall ikke orker å fortsette behandlingen (Aarrestad, 2020; Alqahtani & AlAhmari, 2018; Markussen et al., 2018). I en studie av pasienter med Dystrofia Myotonica behandlet med langtids NIV, viste det seg at pasienter som avsluttet behandlingen etter 5 år, hadde signifikant høyere forekomst av lekkasje, sammenlignet med de som fortsatte behandlingen (Boussaïd et al., 2016).

Tiltak for å redusere lekkasje

Ved å måle størrelsen med en sjablong i stedet for øyemål øker sjansen for å finne korrekt størrelse (Alqahtani & AlAhmari, 2018; Hill & Kramer, 2018a). Hvis du er usikker og valget står mellom to størrelser, bør du først forsøke den minste masken (Hill & Kramer, 2018a).



Maskesjablong

Foto: Vy Rabben

God fiksering av masken og slangen, for eksempel ved å gi pasienten et bord til pustemaskinen med tilhørende respiratorarm, kan redusere lekkasje forårsaket av bevegelse og drag (Alqahtani & AlAhmari, 2018). Tannproteser er ikke konstruert for å brukes under søvn, men en munn uten tenner fører til at munnen faller innover og faren for lekkasje øker. Er masketilpasningen utført med tannproteser i, bør pasienten også bruke disse under behandling (Rolfe, 2019). Det kan være verdt å teste ut en nesemaske i kombinasjon med en hakestropp, for å se om det reduserer lekkasjen når tannprotesen er tatt ut. Et annet dilemma er når pasienten har mye skjegg (Rolfe, 2019). Jeg har opplevd flere tilfeller hvor akkurat det å barbere bort skjegget oppleves som et stort tap. De fleste gjør det likevel etter at de har testet ut hvor vanskelig det er å få masken til å sitte godt til et ansikt dekket av hår. En ukritisk stramming av hodestroppene til masken kan også føre til at lekkasjen øker (Caple, 2017; Rolfe, 2019). Pasienter med lite hode kan ha nytte av å prøve ut hodestropper i mindre størrelser enn det som kommer som standard og disse kan bestilles fra produsentene. Noen ganger har vi også kommet i mål ved å velge masker til barn.

Avslutningsvis er det viktig å påpeke at moderne pustemaskiner kan kompensere for lekkasjer, og det er ikke nødvendigvis slik at all lekkasje må korrigeres. Langtids NIV-behandling kan være effektiv, både med tanke på å redusere CO_2 og føre til tilfredsstillende brukstid, selv om det er lekkasje tilstede. Sykepleieren bør ikke intervenere før det viser seg at lekkasje påvirker behandlingen negativt (Hill & Kramer, 2018b).

Trykksår

«Kurt» var en våre pasienter med KOLS som brukte langtids NIV over flere år. Han hadde god etterlevelse og hadde færre akutte innleggelser etter oppstart av behandling. I likhet med mange pasienter med KOLS og dyspne, ønsket «Kurt» munn- og nesemaske. Fra å være en behandling primært på natt og litt på dagtid, ble masken snart en del av hele døgnet. Før den siste akutte innleggelsen hadde masken påført «Kurt» et alvorlig trykksår over neseryggen. Du kunne nærmeste skimte benstrukturene og det var tydelig at masken med trykk over neseryggen måtte byttes til annen type. Såret måtte ha påført han store smerter, men det var tydelig at åndenød hadde trumfet alt annet i «Kurt» sitt liv. Mine kolleger tilpasset en ny munn- og nesemaske, men uten trykkpunkt over nesen. En av de nyeste maskene i sortimentet vårt, og som har blitt et reddende tiltak for mange såre neser. Såret til «Kurt» kunne endelig begynne å heles.

Munn- og nesemaske uten trykkpunkt over nese
Foto: Vy Rabben

Hva er et trykksår?

I følge European Pressure Ulcer Advisory Panel er trykksår en skade på hud eller underliggende vev begrenset til et lite område, ofte lokalisert til benete strukturer (Alqahtani & AlAhmari, 2018). Videre er trykksår ofte et resultat av vedvarende høyt trykk mot huden, i kombinasjon med friksjon, hypoksi i vevet, og sårbarhetsfaktorer som høy alder og kroniske sykdomstilstander som krever periodevis behandling med steroider (Alqahtani & AlAhmari, 2018; Brill et al., 2018). Sår er en av de hyppigste komplikasjonene (5-30 %) knyttet til NIV-behandling (Carron et al., 2013). Jo flere timer i døgnet pasienten bruker masken, desto mer øker risikoen for sår i ansiktet og spesielt over neseroten (Alqahtani & AlAhmari, 2018; Brill et al., 2018; Schub & Heering, 2018), men også på huden hvor hodestroppen strammer, som for eksempel over øret (Schub & Heering, 2018).

Hvordan forebygge sår?

Valg av riktig maske og god masketilpasning kan forebygge sår (Alqahtani & AlAhmari, 2018; Brill et al., 2018; Caple, 2017; Rolfe, 2019). En hovedregel er å stramme masken så mye som nødvendig for å redusere plagsom lekkasje, men aldri mer enn det absolutt nødvendige (Alqahtani & AlAhmari, 2018; Brill et al., 2018; Hill & Kramer, 2018b). Du kan kontrollere ved å sørge for at du fortsatt har plass til to fingre mellom hode og hodestropp, etter at du har strammet (Alqahtani & AlAhmari, 2018).

I et eksperiment av Brill testet deltagerne flere ulike masker, og trykkpunktet mot neseryggen viste seg å være svært forskjellig ut i fra hvilken av de fire maskene de testet. Dette kan indikere at en-maske-passer-alle er en utilstrekkelig strategi (Brill et al., 2018). Avdelinger som tilbyr LTMV bør derfor ha et solid utvalg av ulike masker fra ulike leverandører og masken må individuelt tilpasses. Det samme eksperimentet viste også at masken måtte strammes mer for å sitte tilstrekkelig, når personen satt enn når masken ble tilpasset i liggende posisjon. Dette kan skyldes at tyngdekraften hjelper på å holde masken tett (Brill et al., 2018; Rolfe, 2019).

Selv om du har lykkes i å finne riktig maske til pasienten, er fortsatt pasienten utsatt for å utvikle sår. Rolfe (Rolfe, 2019) anbefaler derfor LTMV-sykepleiere å følge disse tre rådene;

- Å hjelpe pasienten til å ivareta huden på en god måte
- Å observere og kontrollere huden jevnlig for tegn på sår
- Å la huden hvile ved å rullere på ulike masker

Å beskytte huden ved å holde den tørr og ren, er nødvendig for å forebygge maserasjon og minimere friksjon (Alqahtani, Worsley, & Voegeli, 2018). Vi anbefaler også pasienten til å tørke av masken daglig for å fjerne partikler som kan føre til friksjon. Rutinen kommer i tillegg til en grundig rengjøring av masken en gang i uken. Beskyttende salver vi vanligvis bruker rundt sår på andre steder av kroppen, frarådes fordi de vil kunne påvirke hvor godt masken sitter (Rolfe, 2019).

LTMV-sykepleiere må kunne identifisere sårbare pasienter, observere utsatte områder og anbefale tiltak for å forebygge dannelse av sår (Caple, 2017). Flere randomiserte kontrollerte studier har vist at beskyttende bandasjer, som for eksempel hydrokolloid, transparente film-kompresser, og silikonplater kan forebygge sår sammenlignet med ingen beskyttelse i det hele tatt (Alqahtani & AlAhmari, 2018; Hill & Kramer, 2018b). Erfaringsmessig anbefaler jeg

tynne hudbarriere plaster i en tidlig fase, for å forhindre at røde utsatte områder utvikler seg til sår. Bruk av silikonplater kan fungere, men vær oppmerksom på økende lekkasje, fordi masken ikke lenger ligger inntil huden. Områdene rundt ørene eller på hodet kan beskyttes ved å legge et tøystykke av bomull eller fleece under stroppene for å beskytte huden (Hill & Kramer, 2018a). Fukting av innåndingsluften kan øke risikoen for sår ved at våte kompresser skaper mer friksjon og ved at fuktigheten fører til maserasjon av huden. Økt fuktighet og temperatur i huden, kan gjøre huden mer sårbar for traumer i form av sår og det anbefales derfor å begrense fukting til et minimum for å oppnå komfort (Alqahtani et al., 2018).

I alle tilfeller bør røde neserygger fungere som et varsko-tegn og sykepleieren må kartlegge hva som forårsaker rødheten. Det kan svært ofte skyldes at pasienten ikke har fått tilstrekkelig veiledning i hvordan de tar på seg masken på en god måte for å redusere lekkasje. Jeg anbefaler at man løsner på stroppene hver gang du tar av masken. Neste gang du setter på masken venter du til cushion (eller puten) er godt fylt med luft. Du kan bevege litt på masken og se om den finner en bedre posisjon og deretter begynner du å stramme litt og litt, til lekkasjen opphører.

Pasienter som lider av progredierende muskelsykdommer, men også KOLS-pasienter vil oppleve at bruken av pustemaskin øker i takt med forverring av sykdommen. Kontinuerlig langtids NIV øker risikoen for sår og et viktig forebyggende tiltak er å la huden hvile ved å introdusere ulike masker, som pasienten kan bytte på å bruke (Dorst & Ludolph, 2019; Hess, 2007; Hill & Kramer, 2018a). Jeg har god erfaring med bruk av nesemaske og neseproppper på dagtid og munn-nesemaske på natt. Total ansiktsmasker reduserer også trykket på neseryggen og masken er sterkt anbefalt i akutt behandling (Alqahtani & AlAhmari, 2018). Jeg opplever at det har vært vanskelig å tilpasse denne type maske i langtids NIV. Pasientene forteller ofte at de føler seg innestengte, at de ikke kan bruke briller og at de i stedet opplevde plagsom lekkasje i pannen eller langs kinnet. Vi har også masker med skum, i stedet for silikon-cushion, som kan avlaste neseryggen. Har pasienten fått et sår, må uansett området avlastes og pasienten må få tilpasset en maske med et annet trykkpunkt.

På vårt sykehus har pasienter med raskt progredierende muskelsykdommer konsultasjoner minimum hver 6 måned, i tillegg til at de kan kontakte koordinator/primær kontakt direkte ved behov. Jeg har ofte tenkt i møtet med «Kurt» at vi kunne forebygget såret tidligere, hvis han hadde kontaktet oss, eller omvendt at også KOLS-pasienter blir en del av gruppen vi tar kontakt med jevnlig.

Tørre og irriterte slimhinner

Langtids NIV kan føre til irriterte eller tørre slimhinner, som kan føre til munntørrhet, nesetetthet og/eller økt sekretproduksjon. Tilsvarende som ved forebygging av sår, kan alternering av ulike masker redusere lufttrykket mot for eksempel slimhinnene i nesen (Rolfe, 2019). Min erfaring er at bruk av neseprop-maske hele døgnet nesten alltid fører til irriterte og rennende neser. Jeg anbefaler derfor å bytte mellom neseproppper hvor luften blåser direkte inn i neseborene og nesemaske eller munn- og nesemaske som fordeler luften jevnere for eksempel om natten. Vannbaserte kremer og gele til bruk på lepper og i neseborene, samt saltvannspray kan også lindre symptomene (Gay, 2020; Hill & Kramer, 2018b; Rolfe, 2019). Vi har også anbefalt bruk av oljer i nesen, påført forsiktig på med en bomullspinne. Spesialoljer til nesen får du kjøpt på Apoteket, men du kan også anbefale pasienten å prøve ut matoljer, som olivenolje eller jordnøttolje.

En fukter som varmer og fukter innåndingsluften til pasienten kan være et nødvendig tiltak mot irriterte slimhinner (Gay, 2020; Hill & Kramer, 2018b). De fleste pustemaskiner ment til hjemmebruk kommer med enkle integrerte fuktere og spesialdesignede slanger med varmetråder som forebygger kondens. Fukterne er ofte innstilt på 26-27 grader, men alle nye LTMV-pasienter bør få opplæring i rengjøring av fukter og hvordan de endrer temperatur eller fuktenivå. I de tilfellene hvor pustemaskinen ikke har varmetråder i slangen, finnes det slangeposer for å redusere varmetap og påfølgende kondens.

Øvre luftveis obstruksjoner

Øvre luftveis obstruksjoner hos ALS-pasienter behandlet med langtids NIV, er en viktig årsak til ineffektiv behandling og redusert overlevelse (Georges et al., 2016). Hyppige obstruksjoner av øvre luftvei kan ofte reduseres ved å øke det ekspiratoriske trykket fra maskinen, bytte til annen modus på pustemaskinen og optimalisere nåværende maske med tanke på lekkasje (Georges et al., 2016; Schellhas et al., 2018). LTMV-sykepleiere bør også være oppmerksomme på at hos noen grupper av nevromuskulære pasienter, kan masken i seg selv medføre obstruksjoner. Det er spesielt masker som dekker både munn og nese, som kan føre til at fenomenet oppstår og det skyldes ofte en lukking av glottis og kollaps i larynks, forårsaket av en kombinasjon av svak muskulatur i øvre luftvei, tyngde fra det nedre punktet av masken (Schellhas et al., 2018) og høy luftstrøm/trykk gitt med munn- og nesemaske (Aarrestad, 2020). En munn-nesemaske er ofte praktisk fordi den reduserer lekkasje ut fra munnen, men resultatet kan altså medføre økt forekomst av øvre luftveis obstruksjoner.

Opplæring

Opplæring i langtids NIV og vedlikehold av utstyr er viktig for at pasienten bruker masken på en trygg måte, også etter utskrivning fra sykehuset (Caple, 2017; Rolfe, 2019). God oppfølging fra helsepersonell er identifisert som en faktor som positivt kan påvirke HRQOL (Markussen et al., 2018). Pårørende og andre omsorgspersoner, som brukerstyrt personlige assistenter, hjemmesykepleiere eller ansatte på institusjoner med LTMV-pasienter, må inngå i opplæringsprogrammet (Aarrestad et al., 2012). Å involvere pasienten i behandlingen øker sannsynligheten for å lykkes. Du kan begynne med å undersøke hva pasienten selv forventer av behandlingen, nåværende kunnskap og legge til rette for at pasienten kan få besvart spørsmål (Caple, 2017). Opplæring av pasienten og omsorgspersoner må foregå i god tid før utskrivning, gjerne umiddelbart etter oppstart (Caple, 2017). Det er viktig at pasienten blir tilvent maske og maskin på dagtid, både fordi pasienten er mer mottakelig for informasjon, men også fordi en typisk sykehusavdeling er bedre bemannet på dagtid (Gay, 2020). Caple (Caple, 2017) foreslår at pasienter selv øver på følgende, under veiledning av sykepleier:

- Ta av og på seg maske
- Tilpasse hodestroppene slik at lekkasjen opphører
- Ta av seg maske i en akutt situasjon, for eksempel om pasienten skulle kaste opp, eventuelt kartlegge behovet for nødutløser på masken eller nattevakt

Et systematisk opplæringsprogram, som inkluderer undervisning, enkle e-læringsprogrammer og praktisk utprøving til både pasienten og andre omsorgspersoner, kan øke sannsynligheten for at pasienten fortsetter bruken hjemme (Gay, 2020). Yrkesaktive pasienter med utdanning og som gjennomgår en grundig opplæring under etablering av langtids-NIV, har vist seg å ha økt sannsynlighet for å akseptere behandlingen over tid (Boussaïd et al., 2016).

Tilpasset informasjon

Tilpasset informasjon på et enkelt og forståelig språk ble fremhevet som viktig av brukere i en systematisk oversikt av kvalitative studier av LTMV-pasienter (Ørtenblad et al., 2019). I tillegg var det viktig at denne informasjonen var tilgjengelig i oppstartsfasen, slik at brukeren kunne føle seg trygg på behandlingen, men også trygg på at avgjørelsen om LTMV var riktig.

På vår avdeling har vi utarbeidet enkel og skriftlig pasientinformasjon som sykepleieren gjennomgår med pasienten før utskrivning. Informasjonen inneholder kontaktinformasjon til avdelingen og primærkontakt, og hvem som kontaktes hvis utstyret skulle bli ødelagt eller

pasienten trenger mer forbruksmateriell. Videre er det enkle tips til å løse utfordringer knyttet til masken og oversiktlige rutiner for rengjøring og vedlikehold. I følge Schub (Schub & Heering, 2018) og Caple (Caple, 2017) bør følgende informasjon gjentas før utskrivning:

- Indikasjon for behandling og positive effekter på pasientens respirasjon, søvn og HRQOL
- Funksjonene til pustemaskinen og masken, inkludert justering av hodestropp, rengjøring av maske og hvordan løse mulige komplikasjoner
- Viktigheten av å oppsøke hjelp ved forverring av symptomer

Pårørende – En viktig støttespiller

Jeg har i løpet av mine år som LTMV-sykepleier blitt kjent med mange svært «driftige» og sterke pårørende. Du glemmer aldri møter med personer, som i tillegg til å være ektefelle, foreldre eller barn til en person som er svært syk, også skal fungere som en administrator av brukerstyrte personlige assistenter og hjemmesykepleie. Vi er opptatt av fordelene ved å behandle med LTMV, men mindre oppmerksomme på å vurdere påkjenningen behandlingen vil medføre pårørende og at de derfor må involveres på et tidlig tidspunkt (Crimi, Pierucci, Carlucci, Cortegiani, & Gregoretti, 2019). Pårørende har innflytelse i om NIV-behandlingen lykkes, spesielt i gruppen av pasienter med alvorlige underliggende diagnoser. Videre viser det seg at langtids NIV aksepteres oftere av pasienter som er gift, og at overlevelsesraten er høyere i gifte enn i ugifte pasienter med ALS (Cousins et al., 2013). Selv om LTMV-pasienter ofte får innvilget offentlig hjelp i hjemmet er likevel pårørende en viktig støttespiller. En kontinuerlig tilstedeværelse av hjelpere i hjemmet kan også oppleves som inngripende og belastende. Vi opplever derfor ofte at pårørende ikke ønsker nødvendig hjelp, på for eksempel natt, fordi de ønsker å beholde noen private sfærer. LTMV kan øke HRQOL til for eksempel ALS-pasienter, men ofte opplever familien redusert søvnkvalitet, stress, økte ansvarsoppgaver og forverret HRQOL (Cousins et al., 2013). Stress og sykdomsbyrde hos pårørende betyr ikke at pasientene ikke skal tilbys behandling, men at adekvat undervisning og støtte til pårørende er en nødvendig del av behandlingen vi tilbyr (Hill & Kramer, 2018a).

I følge Crimi (Crimi et al., 2019) og Cousin (Cousins et al., 2013) oppgir ofte pårørende til LTMV-pasienter at de ikke mottar god nok opplæring, at overføring til hjemmet mangler en systematisk plan og at informasjon om ulike teknikker for å løse konkrete problemer er mangelfull. I tillegg opplever de ofte å bli betraktet som passive mottakere og ikke være delaktige i hvordan behandlingen utformes. Informasjon må gå utover prognose og progresjon

av sykdom, og innbefatte praktiske tilnærminger og løsninger på for eksempel sår etter maske, økende forekomst av slim, hvordan løse utfordringer knyttet til lekkasje, og hvem de skal kontakte i spesialisthelsetjenesten om de har behov for å rådføre seg med fagfolk. I tillegg bør pårørende ha tilgang til å ha profesjonelle samtaler med for eksempel psykiatrisk sykepleier eller psykolog (Crimi et al., 2019). På min avdeling vektlegger vi hvor viktig det er å opprette ansvarsgrupper, som møtes jevnlig hos pasienten. Gruppen kan bestå av primærkontakt i spesialisthelsetjenesten, fastlege, teamleder for omsorgsgruppen i hjemmet, pasienten selv og pårørende. Jevnlige møter kan fange opp potensielle problemer og gi en mulighet til å iverksette raske tiltak. I en studie av ALS-pasienter og pårørende var det liten forskjell på pasientens symptomer og mestringsevne, i hvorvidt de aksepterte behandling eller ikke. Der i mot var det signifikant forskjell på pårørende i de to gruppene. I gruppen av NIV-tolerante skåret pårørende høyere både på evnen til å mestre situasjonen og resiliens (Ando et al., 2015)

Både Lindahl (Lindahl et al., 2005) og Brooks (Brooks et al., 2004) finner i sine kvalitative studier av hvordan LTMV påvirker pasienter, at en jevnlig kontakt med kompetent helsepersonell er viktig for å leve et godt liv med respirator. Dette understøttes av Markussen sin studie på HRQOL og LTMV-pasienter (Markussen et al., 2018). Håp, støtte og oppmuntring fra dedikerte helsepersonell gir positiv energi, mens det å bli umyndiggjort og ikke vite sitt eget beste, stjeler energien. Lindahl advarer sykepleiere mot å se seg blinde på fordelene ved medisinsk teknologiske fremskritt, uten å reflektere over hvordan det influerer pasienter, sykepleieren selv og vår praksis. Et holistisk syn på egen sykepleie og omsorgsperspektivet er viktig, selv om vi omgir oss med ny medisinsk teknologi.

KONKLUSJON

Langtids NIV hos pasienter med kronisk hyperkapnisk respirasjonssvikt kan øke både overlevelse og HRQOL. Det er flere faktorer som bidrar til vellykket behandling, blant annet er god masketilpasning essensielt. Masken kan føre til ineffektiv behandling, plagsomme bivirkninger, alvorlige komplikasjoner, redusere compliance og medføre lavere HRQOL. Jeg har valgt å reflektere over hvordan sykepleieren kan bistå pasienten i vellykket masketilpasning i lys av Kim sitt teoretiske rammeverk og spesielt «praksis»-domenet. Sykepleiere kan gjennom å opparbeide seg kompetanse innen LTMV foreslå best mulig maske tilpasset pasientens individuelle situasjon. Videre kan vår utøvelse av faget bidra til å forebygge og behandle komplikasjoner knyttet til maskebehandling, som dødrom-ventilasjon,

klaustrofobi, lekkasje, sår, irriterte slimhinner og øvre luftveis obstruksjoner. Videre er vi også hovedansvarlig i opplæringen og en viktig bidragsyter i å tilrettelegge informasjonen til pasienten. Til slutt har vi en viktig rolle i å inkludere pårørende og legge til rette for at de kan bistå som viktige støttespillere. Sykepleieren med kompetanse i langtids NIV har en viktig rolle i det multidisiplinære arbeidet både under etablering og i oppfølging, for at LTMV-pasienter lykkes med behandlingen.

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Vedlegg 1: Presentasjon av relevante studier og litteratur

Generelt om masketilpasning ved langtids non-invasiv ventilasjon

Forfatter	År	Tittel	Type	Hensikt eller funn	Tidsskrift
Aarrestad med flere	2012	Nasjonal faglig retningslinje for langtids mekanisk ventilasjon (LTMV)	Nasjonal retningslinje	Anbefalinger LTMV	Dokument fra Helsedirektoratet
Aarrestad med flere	2012	Nasjonal faglig veileder for langtids mekanisk ventilasjon (LTMV)	Nasjonal veileder	Anbefalinger LTMV	Dokument fra Helsedirektoratet
Aarrestad	2020	Monitoring long-term nocturnal non-invasiv ventilation for chronic hypercapnic respiratory failure: What are the basic tools?	Phd-avhandling	Hvordan monitorere LTMV-pasienter under oppfølging av behandlingen	Universitetet i Oslo Faculty of Medicine
Alqahtani	2018	Evidence based synthesis for prevention of noninvasive ventilation related facial pressure ulcers	Review	Hva forårsaker sår og hvordan kan helsepersonell forebygge og iverksette tiltak for å forbygge og redusere komplikasjoner knyttet til sår	Saudi Med J
Alqahtani	2018	Effect of Humidified Noninvasive Ventilation on the Development of Facial Skin Breakdown	Experimental design	Non-invasiv ventilasjon med fukting har en potensiell skadelig effekt på hudens barrier-evne, grunnet transepidermal væsketap	Respiratory Care
Ando	2015	Why don't they accept non-invasive ventilation?: Insight into the interpersonal perspectives of patients with motor neuron disease	Kvalitativ studie med semi-strukturerte intervjuer og fenomenologisk analyse	Fire temaer identifisert i hvorfor ALS-pasienter ikke ønsker behandling: • Bevare eget selvbilde • Negativt syn på LTMV • Negative erfaringer med helsepersonell • Syn på at de ikke hadde behov for NIV	British Journal of Health Psychology

Brill	2018	Mask pressure effects on the nasal bridge during short-term noninvasive ventilation	Experimental design	Tyve friske individer testet fire ulike masker med tilhørende sensor som målte trykket mot neseryggen. Trykket mot huden var uavhengig av økning av inspiratorisk trykk fra maskinen, trykket var høyere i sittende stilling enn i liggende og trykket var ulikt hos samme deltager avhengig av type maske	ERJ Open Research
Brooks	2004	User perspectives on issues that influence the quality of daily life of ventilator-assisted individuals with neuromuscular disorders	Kvalitativ: Grounded theory	Viktige perspektiver hos LTMV-pasienter	Canadian Respir Journal
Caple	2020	Noninvasive Assisted Ventilation: Preparing Adult Patients	Database: Nursing Practice and Skills	Kunnskapsbaserte råd vedrørende LTMV og NIV-behandling	Database: Nursing Reference Center Plus
Crimi	2019	Long-Term Ventilation in Neuromuscular Patients: Review of Concerns, Beliefs, and ethical Dilemmas	Thematic Review Series	Anbefalinger knyttet til oppfølging av nevromuskulære pasienter med LTMV	Respiration
Dorst	2019	Non-invasive ventilation in amyotrophic lateral sclerosis	Review	Anbefalinger om LTMV til ALS-pasienter	Therapeutic Advances in Neurological Disorders
Ergan med flere	2019	European Respiratory Society guidelines on long-term home non-invasive ventilation for management of COPD	Klinisk retningslinje	LTMV til KOLS-pasienter: Hvorfor og hvordan?	European Respiratory Journal
Fiorentino	2018	Continuous noninvasive ventilation for respiratory failure in patients with amyotrophic lateral sclerosis: current perspectives	Review	Oppfølging av non-invasiv LTMV hos ALS-pasienter	Degenerative Neurological and Neuromuscular Disease
Gay	2020	Nocturnal ventilatory	Klinisk	Anbefalinger for oppstart av nattlig	UpToDate

		support in COPD	oppslagsverk / Database	respirasjonsstøtte hos pasienter med KOLS	
Hess	2007	Noninvasive ventilation for Neuromuscular Disease	Expert opinion/Editorial/ Fagartikkel	Oversikt over positive og negative faktorer ved ulike masker	Respiratory Care
Hess	2012	The growing role of Noninvasive Ventilation in Patients Requiring Prolonged Mechanical Ventilation	Expert opinion/Editorial/ Fagartikkel	Faktorer for å lykkes med langtids NIV er riktig pasient, riktig valg av maske, rett valg av respirator og innstillinger, kompetanse og ferdigheter hos behandler, motivasjon hos pasient og støtte fra pårørende.	Respiratory Care
Hill & Kramer	2020	Types of noninvasive nocturnal ventilatory support in neuromuscular and chest wall disease	Klinisk oppslagsverk / Database	En gjennomgang av fordeler og ulemper til ulike interface/masker	UpToDate
Hill & Kramer	2018	Troubleshooting problems with noninvasive ventilation	Klinisk oppslagsverk / Database	Ubehag knyttet til maske er den største utfordringen for å tilvenne pasienter NIV Anbefalinger for å redusere komplikasjoner knyttet til såre slimhinner, lekkasje og sår	UpToDate
Hill & Kramer	2018	Practical aspects of nocturnal noninvasive ventilation in neuromuscular and chest wall disease	Klinisk oppslagsverk / Database	Råd for tilpasning av maske spesielt med tanke på muskelsyke pasienter	UpToDate
Lindahl	2005	On becoming dependent on home mechanical ventilation	Kvalitativ: Narrativ	Viktige perspektiver hos LTMV-pasienter	Journal of Advanced Nursing
Rolfe	2019	Non-invasive positive pressure ventilation in the home setting		Kunnskapsbaserte råd vedrørende LTMV og NIV-behandling	British Journal of Community Nursing
Schub	2020	Noninvasive Assisted Ventilation: Bilevel Positive Airway Pressure (BiPAP)	Database: Nursing Practice and Skills	Kunnskapsbaserte råd vedrørende LTMV og NIV-behandling	Database: Nursing Reference Center Plus
Schellas	2018	Upper airway obstruction induced by non-invasive	Retrospective design	Munn og nesemasker kan øke apne-hypopne indeks, spesielt i noen undergrupper av	Sleep and Breathing

		ventilation using an oronasal inferface		nevromuskulære pasienter Et av flere tiltak kan være å bruke nesemaske, eventuelt i kombinasjon med hakstropp	
Ørtenblad	2019	Users` Experience With Home Mechanical Ventilation: A Review of Qualitative Studies	Systematisk oversikt av kvalitative studier	• Økt livskvalitet • Ønske om å bo hjemme • Tvunget til å akseptere LTMV • Flere bekymringer • Samarbeid mellom bruker og omsorgspersoner er utfordrende • Informasjon om teknologien	Respiratory Care