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Patients experience regarding home mechanical ventilation in an outpatient setting

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Abstract

Background: The patient's experience of treatment is a cornerstone of high-quality healthcare, along with clinical safety and effectiveness. We aimed to evaluate the patients' perspectives regarding home mechanical ventilation (HMV) follow up in an outpatient setting and ascertain differences between patients that started HMV in the outpatient setting compared to other settings.

Methods: This cross-sectional study was conducted with patients with chronic respiratory failure under HMV in the Outpatient Ventilation Clinic. Patients filled in a patient experience questionnaire and the S3-NIV questionnaire.

Results: The study included 235 patients (127, 54% male), median 70 [25–75 percentiles 64–76] years) and about half were adapted to HMV in the outpatient setting (117, 49.8%). Patients had a daily ventilator usage of 8.0 [6.0–10.0] hours and have been on ventilator for a median of 35.0 [12.0–66.0] months. Patients reported an overall good experience regarding education at initiation (209 [88.9%] considered the information given was enough), short time to adaptation [104 (44.3%) felt adapted after some hours], with perceived benefits (171 [72.8%] reported less shortness of breath, 158 (67.2%) improved quality of life and 150 (63.8%) less tiredness). Benefits overcame the treatment side-effects (158 [67.2%] reported mucosal dryness, 109 (46.4%) mask sores and 96 (40.9%) leaks). There was no difference in terms of reported health gains, side effects or time to adaptation between adaptation settings, but patients starting HMV in the outpatient setting reported better communication and education at adaptation.

Conclusions: Outpatient setting was perceived as a positive experience, both in HMV initiation and follow up, with good patient-physician communication leading to significant health reported gains, improvement of health status and well-being and good treatment adherence.

Keywords

Noninvasive ventilation, patient reported outcomes, patient experience, hospital outpatient clinic, outpatient setting

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Introduction

Home mechanical ventilation (HMV) is indicated in patients with chronic respiratory failure (CRF) of many causes and its utilization has been increasing both due to widening indications and improved health care setting organization.[1,2] The characteristics of individual with HMV have also changed, from the initial predominantly restrictive indications to a progressive increase of patients with obesity hypoventilation syndrome (OHS), chronic obstructive pulmonary disease (COPD) and overlap syndromes.[2–4] In 2001, the Eurovent trial the estimated prevalence of HMV in Europe of 6.6 per 100,000 people and it was quite variable among countries.[3] In 2021, a German study reported an incidence of HMV of 21.6/100,000 inhabitants[5] while a Swiss study described a prevalence of 38/100,000 inhabitants and a 2.5-fold increase in HMV prescriptions since 2000.[2] In the Eurovent study, the authors hypothesized there were many factors contributing to the variation in estimated prevalence, but it was likely that at least some of the explanation lied in different national attitudes to the potential value of long-term ventilation in both lung and neuromuscular conditions and different national policies and criteria for HMV initiation and reimbursement systems.[3]

Historically and in most relevant studies on HMV, it has been believed that initiation and titration of chronic HMV required a hospital admission.[3,6,7] This approach implies extensive nighttime measurements, high demand for hospital beds and specialized staff, high cost and potential risks of hospital acquired infections. The widening indications for HMV and extended patient survival makes this approach impracticable in resource-limited systems based exclusively in inpatient initiation, adaptation and follow up. Therefore, alternative settings such as home and outpatient have been proposed as alternatives.[8–12]

The patient's experience of treatment is a cornerstone of high-quality healthcare, along with clinical safety and effectiveness. The integration of the patient experience with healthcare delivery and quality evaluation are key steps in moving toward patient-centered and personalized care and promoting more people-centered care has become a growing priority across EU countries in recent years to improve the quality of care and the responsiveness to patients' expectations.[13]

The development of self-reported questionnaires, namely, patient-reported experience measures (PREMs) and patient-reported outcome measures (PROMs), has exponentially increased in the last several years. These two types of questionnaires collect information about the patient's perspective but with distinct purposes. A PREM evaluates patients' perception of their personal experience of the healthcare received, while a PROM assesses the perception of their health status and health-related quality of life.[13]

A recent European Respiratory Society (ERS)/European Lung Foundation (ELF) survey was conducted across 11 European countries and assessed the attitudes and preferences of 687 patients on HMV and of 100 caregivers.[14] A PREM questionnaire was specifically developed for this study and explored four areas: patients' demographic and clinical characteristics; issues influencing compliance, support, training, and education; and requests for improved devices and support. This survey found that formal support was very variable among different European countries, that respondents were positive about the support received at home but that were considerable issues regarding education at adaptation and barriers such as insufficient funding for paid caregivers, equipment and supplies; and negotiating public funding arrangements. Although this survey addressed important issues about patients' experience regarding HMV, there is still important knowledge gaps, especially those being followed in an outpatient setting.

The aim of this study was to evaluate the patients' perspectives regarding HMV follow up in an outpatient setting and ascertain differences between patients that started HMV in the outpatient setting or elsewhere.

Methods

Study design

This cross-sectional study was conducted with patients with CRF under HMV recruited between September 2019 and March 2020 in the Outpatient Ventilation Clinic of the Pneumology Department at Centro Hospitalar de Vila Nova de Gaia/Espinho (Portugal), a tertiary care teaching hospital. Ethical approval was obtained from the Hospital Ethics Committee (Ref 166/2019–2) and written consent was obtained from all included patients.

The outpatient clinic works as a day hospital with several patients being ventilated and monitored at the same time, either at initiation or during follow-up visits. After initiation, all the follow ups are performed in the Outpatient Ventilation Clinic. The clinic staff consists of one pulmonologist and one nurse and often includes the presence of the healthcare professional from the home respiratory care company selected by the patient to provide HMV equipment and ongoing support.

At initiation, patients are adapted and titrated to HMV during daytime for a period of at least 1h with arterial blood gas (ABG) analysis and/or capnography with the ventilator and interface that they will take home. Limited monitoring such as pulse oximetry, cardiac frequency, and blood pressure while the patient is on ventilation is performed. Ventilator set up and adjustments are aimed to correct hypoventilation within patient tolerability and control of

side effects. Patients are then instructed to contact the outpatient clinic if there was any problem or doubt.

Study population

Adult patients diagnosed with CRF, from a wide variety of causes, established on HMV for at least 30 days were eligible for the study. 30 days was defined by the research group as the minimum amount of time on HMV for patients to have a significative experience on HMV so they can answer the questionnaires. Patients were excluded if they refused to participate, were unable to understand or answer patient-reported outcomes or if they had an exacerbation in the preceding 3 months.

Data collection

All data was obtained during scheduled medical visits. Demographic data were obtained from the patient (age, sex) and clinical data from the hospital eletronic health records (body mass index - BMI, disease, time with HMV, ventilation interface, humidifier).

Ventilation parameters and HMV daily usage in the previous 3 months were extracted from the readout of the ventilator's built-in software (ResMed AirView® and Philips Care EncoreAnywhere® platforms). Pulmonary function test data was obtained from the electronic health records if obtained at least 12 months previous to the beginning of the study.

Daytime ABG was obtained according to standard recommendations in sitting patients without ventilation, with the current oxygen flow provided.[15] Patients then filled in the questionnaires.

Questionnaires

Patient experience questionnaire. The self-administered questionnaire regarding patients' perspectives towards HMV was completed. The questionnaire includes 12 questions regarding autonomy handling HMV, perspectives regarding information at initiation, time until adaptation, side effects and benefits related to HMV, perspectives regarding treatment impact on disease and personal well-being. The questionnaire was designed as a multiple choice, with items related to information and perceived side effects and benefits allowing multiple answers (and the two latter having an open-ended option). The number of reported health-related gains and the side effects were summed, ranging from 0 to 12 potential gains and from 0 to 10 potential side effects.

This questionnaire was built by the research team based on most common patient reported information during regular medical visits and results from previous studies (health related gains and side-effects).[1,14,16,17] It was then distributed to 5 pulmonologists to evaluate the suitability of the questionnaire and to 5 people that were not healthcare workers or HMV patients to test for phrasing and comprehension. After minor improvements, it was then tested in 5 HMV patients for easiness to comprehend and relevance of items.

S3-NIV

The S3-NIV Questionnaire[18] is a validated self-administered short questionnaire assessing disease and treatment impact while addressing respiratory complaints, sleep and side-effects. We used this questionnaire as it was developed exclusively for patients with HMV and has been previously validated for the Portuguese population showing good internal consistency.[19] It contains 11 items on a 5-point Likert-scale with the lowest possible score (0) corresponds to the highest impact of disease and treatment, while the highest possible score (10) corresponds to the lowest impact of disease and treatment. The questionnaire has 2 subscores: the "Respiratory Symptoms" subscore is calculated as the average of answered items 1, 4, 5, 6 and 7 multiplied by 2.5 and the "Sleep and Side Effects" subscore is calculated as the average of answered items 2, 3, 8, 9, 10 and 11 multiplied by 2.5. The subscores have the same range and interpretation as the total score.

Statistical analysis

Data are presented, for quantitative variables, with mean and standard deviation or median and interquartile range; categorical variables are presented by absolute frequencies and percentages.

Concerning health-related gain and side-effects, for each patient, the corresponding sum of each category was created, thus constituting quantitative measures of gains and side effects, as a way of comparison.

Normality was assessed by the Kolmogorov-Smirnov test. Patients were categorized into two groups: those whose adaptation was in the outpatient setting and those who were adapted elsewhere (hospital ward, emergency department or home). Comparisons between groups were evaluated through t-test, chi-square, Fisher´s exact test. Nonparametric Mann-Whitney test was used in the case where the parametric assumptions were not valid.

Spearman's rank correlation was used to evaluate the associations between S3NIV score, sleep and NIV related side-effects and sum of side-effects obtained by the satisfaction questionnaire.

Statistical computations were performed with IBM SPSS Statistics for Windows, Version 25.0 (Armonk, NY: IBM Corp.). Two tailed significance assumed for $p<0.05$.

Table 1. Patients' demographic and clinical characteristics and differences between patients that started home mechanical ventilation in the outpatient clinic and elsewhere (n = 235).

	Total	Outpatient adaptation (n = 117)	Adapted elsewhere (n = 117)	p Value
Disease N (%)				
COPD	118 (50.3)	63 (53.4)	55 (46.6)	0.065
OHS	64 (27.2)	23 (36.5)	40 (63.5)	
RCWD	38 (16.2)	21 (55.3)	17 (44.7)	
NMD	15 (6.4)	10 (66.7)	5 (33.3)	
Demographic characteristics				
Age (years) (‡)	70.0 (64.0–76.0)	69.0 (62.5–75.0)	72.0 (64.0–77.0)	0.471
Sex (% male)	127 (54.0)	64 (50.8)	62 (49.2)	0.900
BMI (Kg/m^2) (‡)	32.0 (26.5–39.0)	31.0([25.0–38.0)	33.0 (27.0–40.0)	0.110
Home mechanical ventilation				
Daily usage (hours/day) (‡)	8.0 (6.0–10.0)	8.0 (6.0–10.0)	8.0 (7.0–9.0)	0.368
Months of usage (‡)	35.0 (12.0–66.0)	30.0 (12.0–63.0)	37.0 (14.5–70.3)	
Blood gas analysis				
$PaCO_2$ (mmHg) (⊥)	45.0 (5.6)	45.3 (5.7)	44.8 (5.4)	0.433
HCO3 (mmol/L) (⊥)	27.9 (3.0)	28.0 (3.1)	27.8 (2.9)	0.555
Pulmonary function tests				
FEV_1 (% predicted)	47.0 (32.0–64.3)	46.0 (33.0–59.0)	50.0 (29.8–47.0)	0.090
FVC (% predicted)	65.0 (50.8–75.0)	61.0 (48.0–74.0)	67.5 (53.9–79.0)	0.032
Ventilation parameters				
IPAP (cmH2O) (‡)	20.0 (18-0–24.0)	21.0 (18.0–23.0)	20.0 (18.0–24.0)	0.775
EPAP (cmH2O) (‡)	7.0 (6.0–9.0)	7.0 (6.0–9.0)	7.0 (6.0–8.0)	0.722
BURR (cpm) (‡)	15[14–16]	15[14–16]	15[14–16]	0.393
Interface (%)				
Oronasal mask	175 (74.5)	87 (74.4)	88 (75.2)	0.539
Nasal mask	59 (25.1)	30 (25.6)	27 (23.1)	
Tracheostomy	1 (0.4)	0	1 (0.9)	
Active humidification (%)	75 (31.9)	36 (30.8)	39 (33.3)	0.779

Note: values are presented as mean and standard deviation (⊥) or median and 25–75 percentiles (‡).
Abbreviations: BMI, body mass index; COPD, chronic obstructive pulmonary disease; OHS, obesity-hypoventilation syndrome; RCWD, restrictive chest wall disorders; NMD, neuromuscular disorders; HMV, home mechanical ventilation; FVC, forced vital capacity; FEV1, forced expiratory volume in one second; IPAP, inspiratory positive airway pressure; EPAP, expiratory positive airway pressure; BURR, back up respiratory rate; cpm, cycles per minute.

Results

Patients' characteristics

Of 290 patients on HMV followed in the Outpatient Ventilation Clinic in the study period, 235 (81.0%) patients were included, whose characteristics are described in Table 1.

Most patients were male (127, 54.0%), had a median age of 70.0 [64.0–76.0] years and 50.3% were diagnosed with COPD. Patients had a daily ventilator usage of 8.0 [6.0–10.0] hours, have been on ventilator for a median of 35.0 [12.0–66.0] months, with a median IPAP of 20 [18-0–24.0] and used predominantly oronasal mask (74.5%). About a third of the patients had active humidification (75, 31.9%).

We found a difference regarding place of adaptation within diseases, with neuromuscular disorders (NMD) (66.7%), restrictive chest wall disorders (RCWD) (55.3%) and chronic obstructive pulmonary disease (COPD) (60.4%) more commonly started in the outpatient clinic comparing to OHS (36.5%), this difference was not statistically significant (p = .065).

Patients experience

Regarding the questionnaires, the majority were self-administered (161, 68.5%). Seventy-four patients (31.5%) required help, because they were unable to read, did not bring their reading glasses or were physically too disabled to write (they were helped mostly by relatives). Patients took approximately 8 min to complete the questionnaires.

The patients' experience during the initiation of HMV is described in Table 2.

Over one third of the patients had their first experience with mechanical ventilation in the outpatient ventilation clinic (38.6%), and half were adapted to their current ventilator in the outpatient clinic.

Table 2. Patients' experience regarding initiation of Home Mechanical Ventilation and differences between patients that started home mechanical ventilation in the outpatient clinic and elsewhere (n = 235).

	Total	Outpatient adaptation (n = 117)	Adapted elsewhere (n = 117)	p Value
First place to experiment ventilation				
Outpatient ventilation clinic	90 (38.6)	84 (71.8)	6 (5.1)	<0.001
Hospital ward	71 (30.4)	13 (11.1)	58 (49.6)	
At home	42 (18.0)	10 (8.5)	32 (27.3)	
Emergency room	28 (12.0)	9 (7.7)	19 (16.2)	
Intermediate or intensive care unit	2 (0.9)	1 (0.9)	1 (0.9)	
Place where patients have been adapted to current ventilator				
Outpatient ventilation clinic	117 (50.0)	117 (100)		<0.001
Hospital ward	59 (25.2)		59 (25.2)	
At home	47 (20.1)		47 (20.1)	
Emergency room	11 (4.7)		11 (4.7)	
Education about ventilation at HMV initiation				
The information provided was enough	209 (88.9)	109 (93.2)	99 (84.6)	0.038
I Would have liked to have more information	20 (8.5)	7 (6.0)	13 (11.0)	0.160
I Was told the treatment advantages	169 (71.9)	96 (82.1)	72 (61.5)	0.001
I Was told the treatment potential disadvantages or side-effects	109 (46.4)	64 (54.7)	44 (37.9)	0.009
I Was shown how the ventilator works	186 (79.1)	101 (86.3)	84 (71.8)	0.006
My caregiver was shown how the ventilator works	105 (44.7)	57 (48.7)	48 (41.0)	0.230
Time to adaptation perceived by the patient				
Some hours	104 (44.3)	55 (47.0)	49 (41.9)	0.119
Less than 15 days	85 (36.2)	35 (29.9)	49 (41.9)	
15 days to 3 months	32 (13.6)	16 (13.7)	16 (13.7)	
More than 3 months	8 (3.4)	6 (5.1)	2 (1.7)	
I Am still not adapted to the ventilator	6 (2.6)	5 (4.3)	1 (0.9)	
Other patients' presence in the outpatient clinic helped the adaptation				
Yes	111 (47.4)	52 (44.4)	59 (50.4)	0.617
No	27 (11.5)	14 (12.0)	12 (1.7)	
It was indifferent	96 (41.0)	51 (43.6)	45 (38.5)	

Abbreviations: HMV, home mechanical ventilation. Data presented as n (%).

Most patients report good communication with the physician and health team and education about ventilation management at initiation, which was significantly better in patients that started HMV in the outpatient setting.

Over ¾ of patients (80.5%) described a period to be adapted or comfortable with the ventilator of less than 15 days. There was no statistical difference between place of adaptation and time that the patients felt adapted to the ventilator (47.0% felt they were adapted after a few hours in the outpatient setting vs 47.1% in other adaptation settings, p = 0.119).

Regarding the experience during the follow up period, including health-related benefits and side-effects of HMV, results are described in Table 3, divided by place of adaptation to HMV.

The vast majority of patients (191, 81.3%) considered themselves to be autonomous in ventilator handling.

Most common perceived health related gains were shortness of breath reduction (171,72.8%), quality of life improvement (158, 67.2%), reduction of tiredness (150, 63.8%) and sleepiness (128, 54.5%), a quieter sleep (141, 6o %) and a reduction of infections (118, 50.2%).

On the other hand, most common side-effects were mucosal dryness (158, 67.2%), mask sores (109, 46.4%) and leaks (96, 40.9%).

There was no significant difference in reported health gains or side effects concerning adaptation setting.

Over 80% of patients report that their health status and well-being improved after they started with HMV and all but 4 would recommend the treatment to a relative or friend if indicated.

No difference between reported side effects and sex (male 2.1 vs female 2.4, p = .14) was observed but women perceived a higher number of benefits than men (5.3 vs 4.5, p = .008).

Table 3. Patients' experience regarding perceived health-related benefits and side effects of long-term Home Mechanical Ventilation and differences between patients that started home mechanical ventilation in the outpatient clinic and elsewhere (n = 235).

	Total	Outpatient adaptation (n = 117)	Adapted elsewhere (n = 117)	p value
Person handling the ventilator				
Me	191 (81.3)	91 (77.8)	100 (85.5)	0.048
Me but I need help	14 (6.0)	7 (6.0)	7 (6.0)	
A spouse or a relative	26 (11.1)	16 (13.7)	10 (8.5)	
A professional caregiver	3 (1.7)	3 (2.5)	0	
Advantages or health-related gains after HMV initiation				
Less shortness of breath	171 (72.8)	82 (70.1)	88 (75.2)	0.379
More quality of life	158 (67.2)	72 (61.5)	77 (65.8)	0.464
Less tiredness	150 (63.8)	79 (67.5)	78 (66.7)	0.889
My sleep is quieter	141 (60.0)	71 (60.7)	69 (59.0)	0.790
More awake during daytime	128 (54.5)	65 (55.6)	63 (53.8)	0.793
Less infections	118 (50.2)	56 (47.9)	61 (52.1)	0.513
Less hospital admissions	104 (44.2)	45 (38.5)	58 (49.6)	0.122
Less cough	86 (36.6)	45 (38.5)	41 (35.0)	0.588
Less oxygen needs	52 (22.1)	22 (18.8)	30 (25.6)	0.208
Less costs of treatment	34 (14.5)	14 (12.0)	20 (17.1)	0.266
Sum of perceived advantages or health-related gains	—	4.73	5.00	0.415
Disadvantages or side effects in the preceding week				
Mucosal dryness	158 (67.2)	84 (71.8)	74 (63.2)	0.163
Mask sores	109 (46.4)	58 (49.6)	50 (42.7)	0.294
Leaks	96 (40.9)	45 (38.5)	50 (42.7)	0.506
Ventilator noise	40 (17.0)	14 (12.0)	26 (22.2)	0.037
The ventilator bothers my bed partner	38 (16.2)	23 (19.7)	15 (12.8)	0.156
Electricity costs	25 (10.6)	14 (12.0)	11 (9.4)	0.526
Ventilator too strong/pressure too high	25 (10.6)	11 (9.4)	14 (12.0)	0.526
Claustrophobia	19 (8.1)	10 (8.5)	9 (7.7)	0.811
My sleep is more agitated	18 (7.7)	11 (9.4)	7 (6.0)	0.326
Less sleep time	2 (0.8)	1 (0.9)	1 (0.9)	1.0
Sum of perceived disadvantages or side effects	—	2.31	2.19	0.563
Health status after HMV initiation				
Improved	201 (85.5)	98 (83.8)	102 (87.1)	0.703
Not changed	31 (13.2)	2 (1.7)	1 (0.9)	
Worsened	3 (1.3)	17 (14.5)	14 (12.0)	
Global well-being after HMV initiation				
Improved a lot	122 (51.9)	61 (52.1)	60 (51.3)	0.672
Improved a little	90 (38.3)	42 (35.9)	48 (41.0)	
Not changed	20 (8.5)	12 (10.3)	8 (6.8)	
Worsened a little	3 (1.3)	2 (1.7)	1 (0.9)	
Worsened a lot	0	0	0	
Recommend the treatment to a relative or friend, if indicated				
Yes	229 (98.3)	114 (97.4)	114 (97.4)	1.0
No	4 (1.7)	2 (1.7)	2 (1.7)	
S3-NIV questionnaire (‡)				
Total score	7.3 (6.1–8.4)	7.5 (5.9–8.5)	7.3 (6.1–8.2)	0.909
Sleep and NIV related side effects subscore	7.9 (6.7–9.0)	7.9 (6.3–9.2)	7.9 (6.7–8.8)	0.913
Respiratory symptoms subscore	7.0 (5.5–8.0)	7.0 (5.0–8.3)	7.0 (5.5–8.0)	0.756

Data presented as n (%) or median or 25–75 percentiles (‡).

Abbreviations: BMI, body mass index; COPD, chronic obstructive pulmonary disease; OHS, obesity-hypoventilation syndrome; RCWD, restrictive chest wall disorders; NMD, neuromuscular disorders; HMV, home mechanical ventilation.

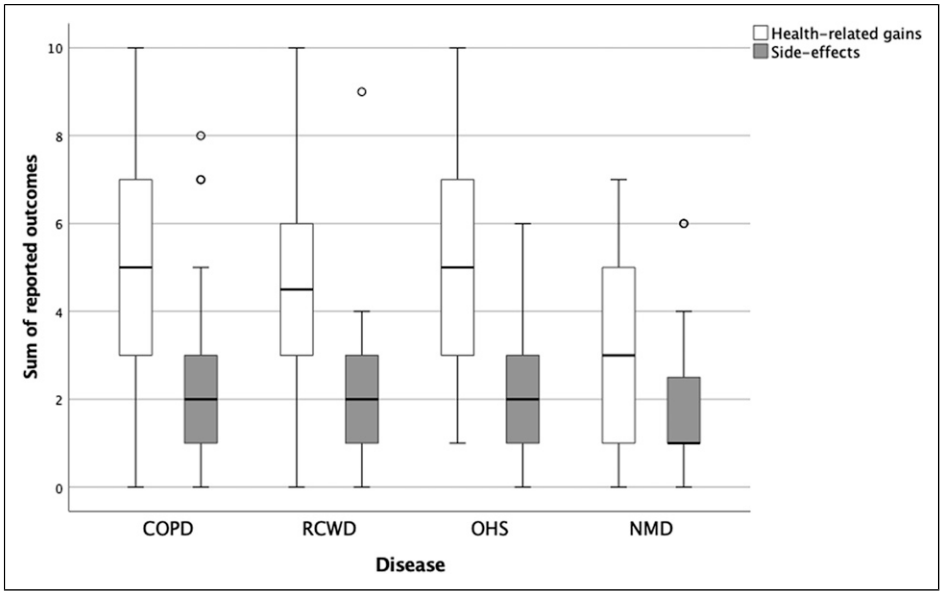

Figure 1. Sum of perceived benefits or health-related gains and reported side-effects by disease Abbreviations: COPD, chronic obstructive pulmonary disease; OHS, obesity-hypoventilation syndrome; RCWD, restrictive chest wall disorders; NMD, neuromuscular disorders.

There were no significant differences in the perception of HMV impact on disease or personal well-being between sexes.

Overall, patients reported significantly more benefits or health-related gains (mean number 4.9) than side-effects of HMV (mean 2.2). We found that patients with NMD recognize a significantly lower number of advantages of ventilation (mean 3.1) when comparing to COPD (5.1, p = .018) and OHS (5.1, p = .028) patients with no difference to RCWD (4.5, p = .276).

There was no statistical difference in number of reported side-effects across diseases (COPD 2.3; OHS 2.3, RCWD 2.1 NMD 2.0), p = .67 (Figure 1).

We found no statistical difference of ventilation impact in the disease or personal well-being across different diseases.

There was no difference in terms of reported health gains and side effects and S3NIV score between adaptation settings (Figures 2 and 3).

There is a moderate correlation between the sleep and NIV related side effects subscore and the reported number of side effects in the satisfaction questionnaire (r=−0.42, p < .001) but a lower correlation to the total score (r=−0.32, p < .001).

Discussion

The results of this study demonstrate that overall patients with HMV followed in an outpatient follow up setting report a good experience regarding education at initiation, time to adaptation, with perceived benefits that considerably overcome the side-effects of treatment and with perceived improved in their health status and well-being and they would largely recommend it to their relatives or friends, if needed.

The outpatient setting has not been thoroughly studied, especially in HMV adaptation. This study also showed that patients initiated in an outpatient setting reported better communication and ventilator education with no difference in the time needed to adapt. These results suggest that, along with perceived benefits and health reported gains and good treatment adherence, the outpatient setting is perceived as a positive patient experience, both in HMV initiation and follow up.

Our study found that half of the HMV users had COPD, which is consistent with recent studies, revealing an increase in prescription practices in these patients.[2,19–22] The high prevalence of COPD and obesity-hypoventilation syndrome patients can explain the high autonomy described by the patients when handling their ventilator.

Comparing to the ERS/ELF study,[14] our study population reported receiving greater education (88.9% vs 32%) and demonstration of how the ventilator worked to them (79.1% vs 29% and their caregivers (44.7% vs 28%) and half were observed during the adaption to the current ventilator while only 18% in the ERS/ELF survey. This European survey did not specify the place of adaptation/initiation of ventilation but considering that the vast majority of respondents were from countries with mainly inpatient initiation, this might explain some of the differences in the results. A recent review on PREMs in patients with home respiratory therapies, such as oxygen and ventilation,

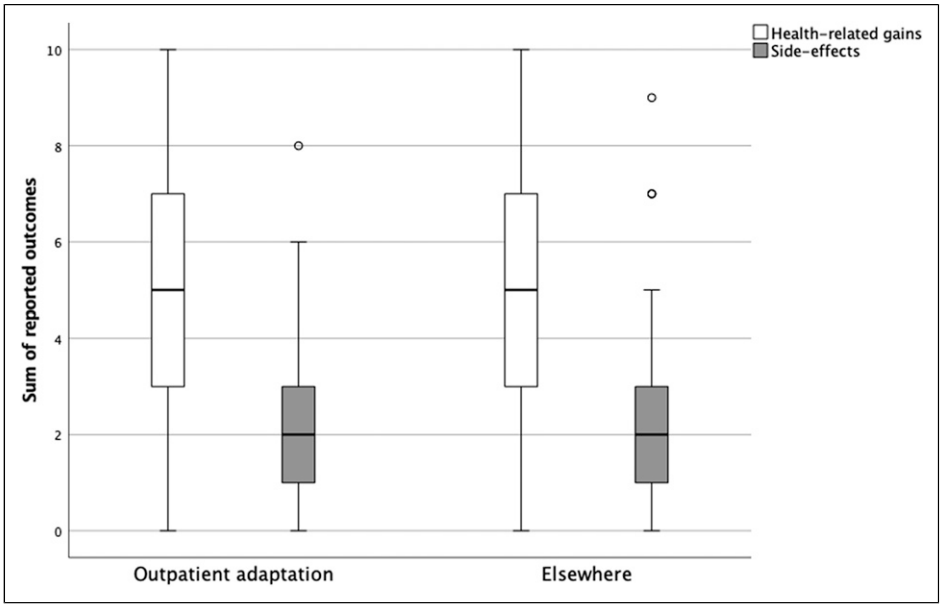

Figure 2. Sum of perceived benefits or health-related gains and reported side-effects by place of adaptation.

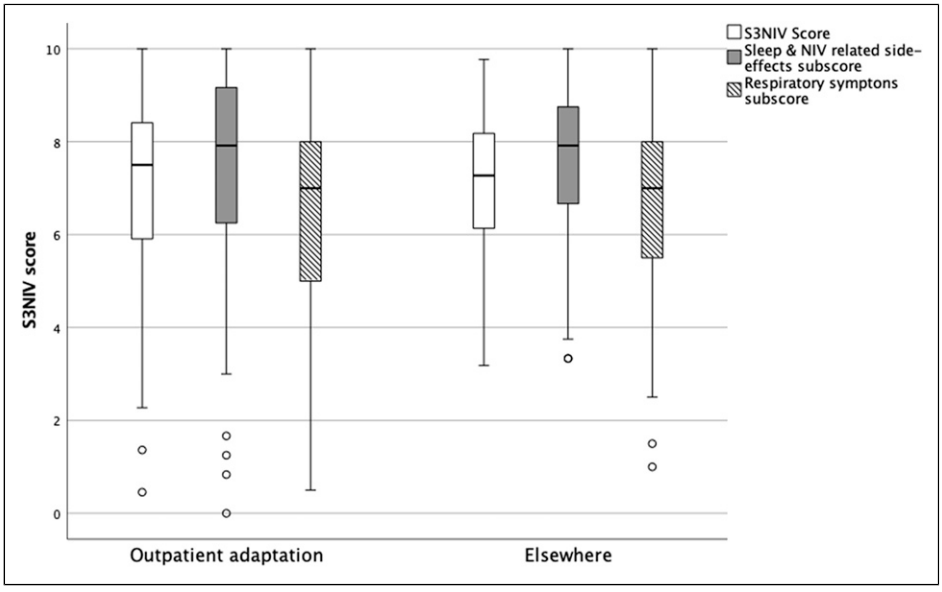

Figure 3. S3-NIV score and subscores by place of adaptation.

found that education, training, support, and caregiver involvement were important key-points in facilitating the patient's treatment experience and adherence.[23] One qualitative study on patients' experience with long-term oxygen and HMV described that physicians had mostly a paternalistic approach at prescription.[24] Since our population reported good communication with the healthcare team and inclusion of caregivers, this may help explain our patients' positive experience.

Although there are some differences concerning time to adaptation, we found that almost half of the patients reported they were adapted after only a few hours and ¾ needing less than 15 days. Home mechanical ventilation initiation can be a challenging period for patients and caregivers and require adaptation different periods to a new reality, with an impact of technology in everyday life.[25] This adaptation period has been insufficiently studied. As a therapy highly dependent on patient

adherence (and all relevant changes in one's life need time to adapt), it seems reasonable that allowing (and supporting) an adaptation period to HMV may lead to better tolerance and outcomes. In a recent trial with home initiation, both groups increased their compliance from 3 to 6 months, and the difference was more relevant in the impatient adaptation group.[8]

Patients reported large perceived benefits of HMV, most commonly reduction of their shortness of breath, better quality of life, less tiredness and better quality of sleep. These benefits largely outnumber the reported side-effects most importantly mucosal dryness, mask sores and leaks. This imbalance towards positive perspective probably explains the high adherence of this population (median 8h/d) and time on HMV (median 35 months). Other studies in quality of life have reported similar results regarding usage.[26,27] There was no difference in the number of side effects reported by disease group. However, NMD patients recognized significantly lower health gains than COPD and OHS patients. This was expected as patients with NMD have a significant burden of disease and dependency, which has impact on patients' perspectives.[25]

The overall positive patient perspective is corroborated with the results of the validated S3-NIV questionnaire, as patients score on the upper third of the scale in the total score, respiratory symptoms and sleep and NIV related side effects subscores. These results are consistent with previous studies with this tool in similar populations.[18,19]

There might be some potential limitations to this study. Firstly, the sample size was relatively small, although it was similar to other studies regarding patient reported outcomes.[26,27] Secondly, the patient experience questionnaire used was developed specifically for this study given the absence of a validated questionnaire on the topic Nevertheless, the authors feel that the global results are reliable and solid. In future, PREMs regarding HMV need to be developed in order to standardize the assessment of patient experience and allow comparison among studies. Thirdly, patients experience was reported retrospectively, and a variable time elapsed since the adaptation. This may lead to some memory bias, especially in recalling events that happened some years ago. Fourthly, we combined settings with different specificities such as inpatient (ward/emergency room) and home initiation for comparison. Further studies are needed to compare specifically outpatient and home settings, as they share more organization and logistical similarities. And lastly, almost a third of patients need help in answering the questionnaire and the impact of having a relative or caregiver helping with the questionnaire filling is uncertain. However, this is common in studies regarding patient reported outcomes and experience measures, especially in frail populations.[26,27]

Conclusions

The results of this study showed that the outpatient setting was perceived as a positive experience, both in HMV initiation and follow up, with good patient-physician communication leading to significant health reported gains, improvement of health status and well-being and good treatment adherence. It also demonstrated that patients initiated in an outpatient setting reported better communication and ventilator education with no difference in the time needed to adapt.

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