

Original paper

Prevalence and clinical significance of deventilation syndrome (DVS) in patients receiving long-term home non-invasive ventilation: A questionnaire-based pilot study

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ABSTRACT

INTRODUCTION: Deventilation syndrome (DVS), defined as increased dyspnoea after cessation of prolonged non-invasive ventilation (NIV), remains a diagnostic and therapeutic challenge.

Knowledge of its pathophysiology, prevalence and treatment is limited. This study aimed to characterise patients receiving home NIV, determine DVS prevalence and explore associated factors.

MATERIAL AND METHODS: This nationwide questionnaire-based observational study included patients treated within a home NIV programme and their attending physicians. DVS was defined using criteria based on the modified Borg scale/visual analogue scale and oxygen saturation changes after mask removal. Clinical and ventilatory variables were compared between patients with and without DVS.

RESULTS: Sixty-five patients were included. DVS was identified in 21 patients (32.3%). Patients with DVS had greater dyspnoea intensity after NIV discontinuation and more often reported dyspnoea lasting more than one hour, immediate discomfort after mask removal and dyspnoea-related limitation of daily functioning. Achieved pressure support was higher in the DVS group than in patients without DVS (15.26 ± 4.78 vs 12.31 ± 3.68 cmH₂O; $p=0.020$). In exploratory logistic regression, higher achieved pressure support was associated with increased odds of DVS (OR 1.20 per 1 cmH₂O; 95% CI 1.02–1.41; $p=0.031$). BMI, Mallampati score, frailty, underlying diagnosis, NIV treatment duration and respiratory rate were not significantly associated with DVS.

CONCLUSIONS: DVS affected approximately one-third of patients receiving home NIV and was associated with substantial post-ventilation symptoms. Higher achieved pressure support emerged as the main ventilatory correlate of DVS and requires further investigation.

KEYWORDS

deventilation syndrome, non-invasive ventilation, home mechanical ventilation, dyspnoea, chronic respiratory failure, chronic obstructive pulmonary disease

INTRODUCTION

Long-term home non-invasive ventilation (NIV) is an established treatment option for selected patients with chronic respiratory failure, particularly in chronic hypercapnic respiratory failure related to chronic obstructive pulmonary disease (COPD) and other causes of alveolar hypoventilation [1,2]. Although NIV may improve gas exchange and symptoms such as dyspnoea in many patients, some patients experience worsening dyspnoea shortly after discontinuation of ventilatory support. This phenomenon has been described as deventilation syndrome (DVS), usually defined as increased dyspnoea occurring after cessation of prolonged NIV therapy [3,4].

Despite growing clinical interest, DVS remains insufficiently characterised. Published data are limited, mostly derived from small COPD-focused cohorts, and a universally accepted diagnostic definition is not yet available [3,4,5,6]. Previous studies have used different diagnostic thresholds, most commonly based on the modified Borg scale, including either an absolute dyspnoea score after mask removal or an increase in dyspnoea intensity compared with baseline [3,4,5,6]. However, dyspnoea is inherently subjective and may be influenced by respiratory mechanics, anxiety, ventilator settings, patient-ventilator interaction and the underlying cause of respiratory failure. Therefore, reliance on a single symptom scale may not fully capture the clinical complexity of DVS.

The pathophysiology of DVS is also not fully understood. Proposed mechanisms include dynamic or NIV-induced hyperinflation, patient-ventilator asynchrony, excessive inspiratory pressure support, altered respiratory drive after NIV discontinuation and respiratory muscle dysfunction [3,5,6]. The lack of standardised diagnostic criteria and objective markers limits both recognition of the syndrome in routine clinical practice and the development of targeted therapeutic strategies.

The aim of this study was to clinically characterise patients treated with long-term home NIV, determine the prevalence of DVS in this population, and explore potential clinical and ventilatory factors associated with the occurrence of DVS.

MATERIAL AND METHODS

This was a nationwide, retrospective, questionnaire-based, observational study conducted among adult patients receiving long-term home NIV due to chronic obstructive pulmonary disease, obstructive sleep apnea, obesity hypoventilation syndrome and chest deformities. Data were collected using anonymous paper questionnaires completed by patients treated within a home NIV programme and by the physicians responsible for their care. The study was performed in patients in a clinically stable phase of the disease.

The questionnaire consisted of two complementary parts. The first part, completed by the physician, included 31 questions concerning demographic and clinical characteristics, the underlying disease leading to chronic respiratory failure, comorbidities, smoking history, duration of home NIV treatment, ventilator settings, oxygen therapy, oxygen saturation after mask removal, dyspnoea intensity assessed with the modified Borg scale or visual analogue scale (VAS), and frailty assessed using the Clinical Frailty Scale (CFS). The second part, completed independently by the patient, included 30 questions focused on the presence, timing and severity of dyspnoea after NIV discontinuation, associated discomfort, functional limitation, anxiety related

to dyspnoea, quality of life, physical capacity, and symptoms of anxiety and depression. The questionnaires were validated by five external experts in NIV and are provided as supplementary files.

Based on available literature and the clinical concept of post-NIV dyspnoea exacerbation [3,4,5,6], DVS was defined as the presence of at least one of the following criteria: 1) an increase in dyspnoea intensity by at least 2 points on the modified Borg scale after mask removal, either immediately or within the first hour, compared with afternoon dyspnoea in patients not using NIV during the day; 2) dyspnoea intensity of at least 4 points on the modified Borg scale occurring immediately after NIV discontinuation; or 3) a decrease in oxygen saturation of at least 4 percentage points immediately after mask removal compared with oxygen saturation throughout the day, excluding the first hour after NIV cessation, accompanied by dyspnoea immediately after mask removal. Due to the lack of a widely accepted, detailed definition of DVS, patients meeting at least one of these criteria were classified as having DVS.

Continuous variables were presented as mean $\pm$ standard deviation or median with interquartile range (IQR), depending on data distribution. Normality was assessed using the Shapiro-Wilk test. Comparisons between patients with and without DVS were performed using Student's t test or the Mann-Whitney U test, as appropriate. Categorical variables were presented as numbers and percentages and compared using the chi-square test or Fisher's exact test. Exploratory univariable logistic regression was used to assess associations between selected clinical and ventilatory parameters and the occurrence of DVS. Results were expressed as odds ratios (ORs) with 95% confidence intervals (CIs) where applicable. A p-value <0.05 was considered statistically significant.

The study was conducted in accordance with the principles of the Declaration of Helsinki and received a positive opinion from the local Bioethics Committee of the Medical University of Silesia in Katowice, Poland: BNW/NWN/0052/KB290/23/24.

RESULTS

Study population and prevalence of DVS

The study cohort included 65 patients treated with home NIV. DVS was identified in 21 patients (32.3%), while 44 patients (67.7%) did not meet the DVS criteria. The overall cohort had a median age of 70.0 years [IQR 64.0-75.0] and a median BMI of 31.1 kg/m² [IQR 25.4-35.6]. The median duration of treatment within the home NIV programme was 35.0 months [IQR 17.5-45.5], and the median average daily NIV use was 8.5 h/day [IQR 7.9-10.0].

Baseline clinical characteristics according to DVS status

There were no statistically significant differences between patients with and without DVS in terms of age, BMI, frailty assessed with the CFS, Mallampati score, Charlson Comorbidity Index (CCI), or underlying cause of chronic respiratory failure (Table I). Age was comparable between groups (median 71.0 [67.0-74.0] vs 70.0 [63.3-76.0] years in the DVS and non-DVS groups, respectively; $p=0.861$). BMI also did not differ significantly (median 31.3 [24.9-33.6] vs 30.9 [25.6-36.6] kg/m²; $p=0.590$). Similarly, Mallampati class (median 2.0 [2.0-3.0] vs 2.0 [1.0-3.0]; $p=0.440$) and CFS score (median 4.0 [3.0-5.0] in both groups; $p=0.296$) were not associated with DVS. The distribution of chronic respiratory failure aetiology, including COPD, obesity hypoventilation syndrome and obstructive sleep apnoea, was also similar between groups ($p>0.05$).

Table I. Clinical, ventilatory and symptom-related characteristics according to deventilation syndrome status

Variable	Available n No DVS/DVS	No DVS	DVS	p-value
Demographic and clinical characteristics				
Age, years	42/21	70 [63.2-76]	71 [67-74]	0.861
Body mass index, kg/m ²	39/19	31.5 ± 8.3	30.3 ± 6.6	0.590
Clinical Frailty Scale	41/21	4 [3-5]	4 [3-5]	0.296
Mallampati score	40/18	2 [1-3]	2 [2-3]	0.440
COPD as underlying diagnosis	44/21	27/44 (61.4%)	16/21 (76.2%)	0.237
Obesity hypoventilation syndrome	44/20	8/44 (18.2%)	3/20 (15%)	1.000
Obstructive sleep apnoea	44/20	9/44 (20.5%)	5/20 (25%)	0.749
NIV exposure and ventilatory parameters				
Duration of home NIV, months	35/20	35 [29-39.5]	35.5 [13.8-66.8]	1.000
Average daily NIV use, h/day	43/19	8.2 [7.7-9.2]	10 [8-11.8]	0.089
Daytime NIV use at patient initiative	41/20	17/41 (41.5%)	12/20 (60%)	0.174
Achieved IPAP, cmH ₂ O	38/17	20.3 ± 4.5	23.2 ± 5.7	0.050
Achieved pressure support (IPAP - EPAP), cmH ₂ O	37/15	12.3 ± 3.7	15.3 ± 4.8	0.020
Achieved respiratory rate, breaths/min	36/14	16 [15-18]	17 [16-18]	0.199
SpO ₂ immediately after mask removal, %	37/21	96 [92-97]	93 [91-96]	0.093
SpO ₂ one hour after mask removal, %	35/20	93 [91.5-95]	92.5 [91.5-94.2]	0.378
Post-NIV symptom burden				
Borg/VAS immediately after mask removal	40/21	0 [0-1.2]	4 [3-8]	<0.001
Borg/VAS one hour after mask removal	40/21	0 [0-2]	4 [2-5]	<0.001
Dyspnoea >1 h after NIV termination	38/20	7/38 (18.4%)	12/20 (60%)	0.001
Immediate discomfort after mask removal	39/17	12/39 (30.8%)	13/17 (76.5%)	0.002
Dyspnoea limiting daily functioning	38/17	23/38 (60.5%)	16/17 (94.1%)	0.012

Data are presented as mean ± SD, median [IQR] or n/N (%), as appropriate. Percentages are calculated from available data.

Abbreviations: COPD, chronic obstructive pulmonary disease; DVS, deventilation syndrome; EPAP, expiratory positive airway pressure; IPAP, inspiratory positive airway pressure; IQR, interquartile range; NIV, non-invasive ventilation; OHS, obesity hypoventilation syndrome; SD, standard deviation. P-values were calculated using Student's t test, Mann-Whitney U test, chi-square test or Fisher's exact test, as appropriate.

NIV exposure and ventilatory parameters

The duration of home NIV treatment did not differ according to DVS status (median 35.5 [13.8-66.8] vs 35.0 [29.0-39.5] months). Patients with DVS tended to use NIV for a longer average daily duration (10.0 [8.0-11.8] vs 8.2 [7.7-9.3] h/day), although this difference did not reach statistical significance ($p=0.089$).

Among ventilatory parameters, achieved driving pressure/pressure support (PS=IPAP-EPAP) was significantly higher in patients with DVS than in those without DVS (mean 15.26 ± 4.78 vs 12.31 ± 3.68 cmH₂O; $p=0.020$), corresponding to a mean between-group difference of 2.95 cmH₂O (95% CI 0.48-5.42). The median achieved driving pressure was 14.20 [11.75-17.80] cmH₂O in the DVS group and 11.40 [10.80-15.00] cmH₂O in the non-DVS group (Figure 1). Achieved IPAP was also higher in the DVS group, with a borderline unadjusted association (24.0 [18.0-27.0] vs 21.0 [17.1-23.3] cmH₂O; $p=0.050$). In contrast, set IPAP, set driving pressure, achieved and set respiratory rate, EPAP, and the proportion of patient-triggered breaths were not significantly different between groups ($p>0.05$).

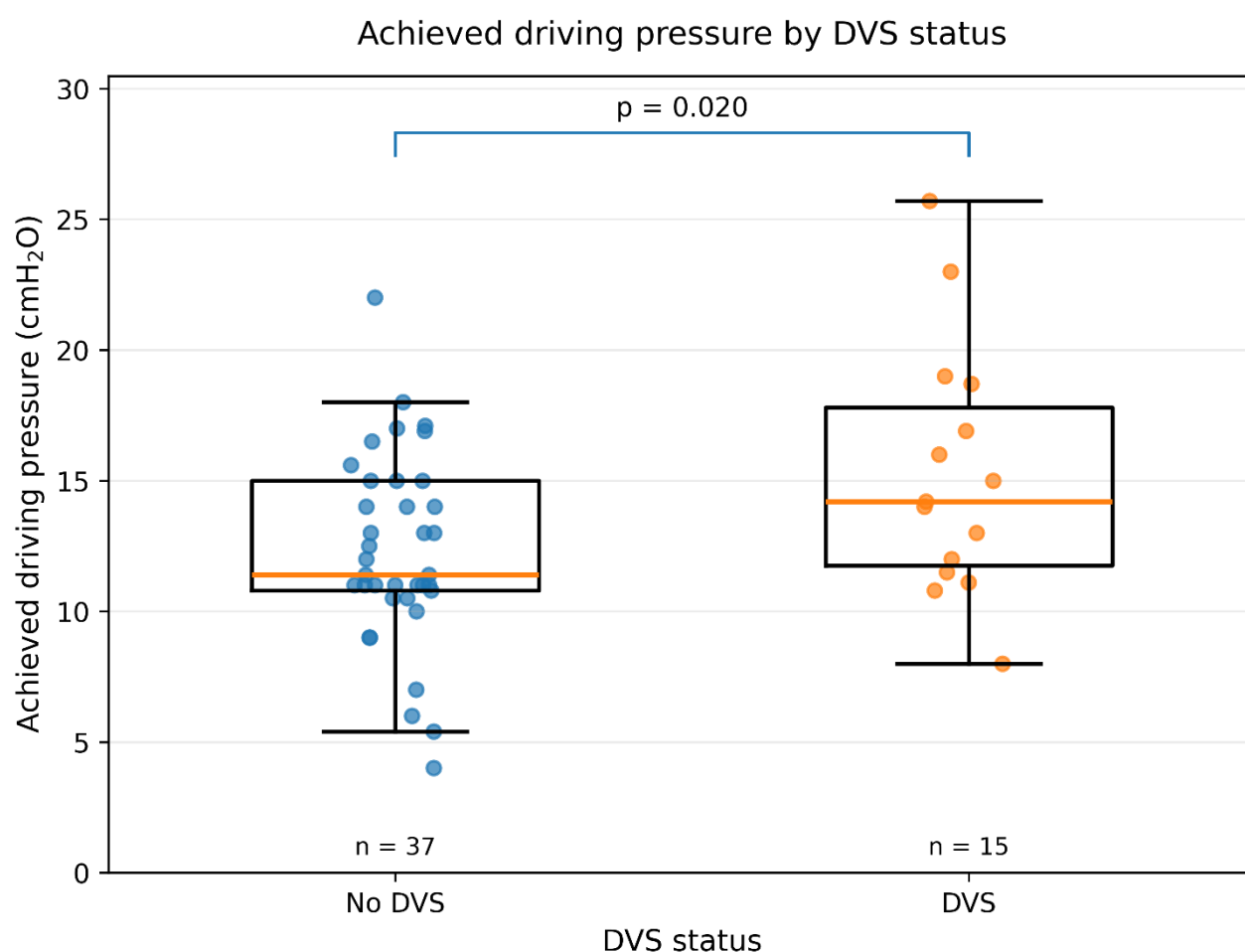


Fig. 1. Achieved driving pressure according to deventilation syndrome status. Boxes represent median and interquartile range; individual points represent patients. DVS - deventilation syndrome.

Oxygenation after NIV discontinuation

Fifty-five percent of the patients received concomitant oxygen therapy during NIV therapy. Mean oxygen saturation immediately after mask removal tended to be lower in patients with DVS (93.0 [91.0-96.0] vs 96.0 [92.0-97.0]%; $p=0.093$), but this difference did not reach statistical significance. Oxygen saturation after one hour was similar between groups (92.5 [91.5-94.3] vs 93.0 [91.5-

95.0]%; $p=0.378$), as was the calculated change in oxygen saturation between the immediate and one-hour measurements ($p=0.487$).

Symptom burden after NIV discontinuation

Patients with DVS had markedly higher dyspnoea intensity after NIV discontinuation. The Borg/VAS score immediately and one hour after mask removal was higher in the DVS group than in the non-DVS group. Categorical symptom variables showed concordant results (Figure 2).

Dyspnoea lasting more than one hour after NIV termination was reported in 12/20 patients with DVS (60.0%) compared with 7/38 patients without DVS (18.4%; $p=0.001$). Immediate discomfort after mask removal occurred in 13/17 patients with DVS (76.5%) versus 12/39 patients without DVS (30.8%; $p=0.002$). Dyspnoea limiting daily functioning was also more frequent in the DVS group (16/17, 94.1%) than in the non-DVS group (23/38, 60.5%; $p=0.012$). Use of NIV during the daytime at the patient's initiative was numerically more common among patients with DVS (60.0% vs 41.5%), but this difference was not statistically significant ($p=0.174$).

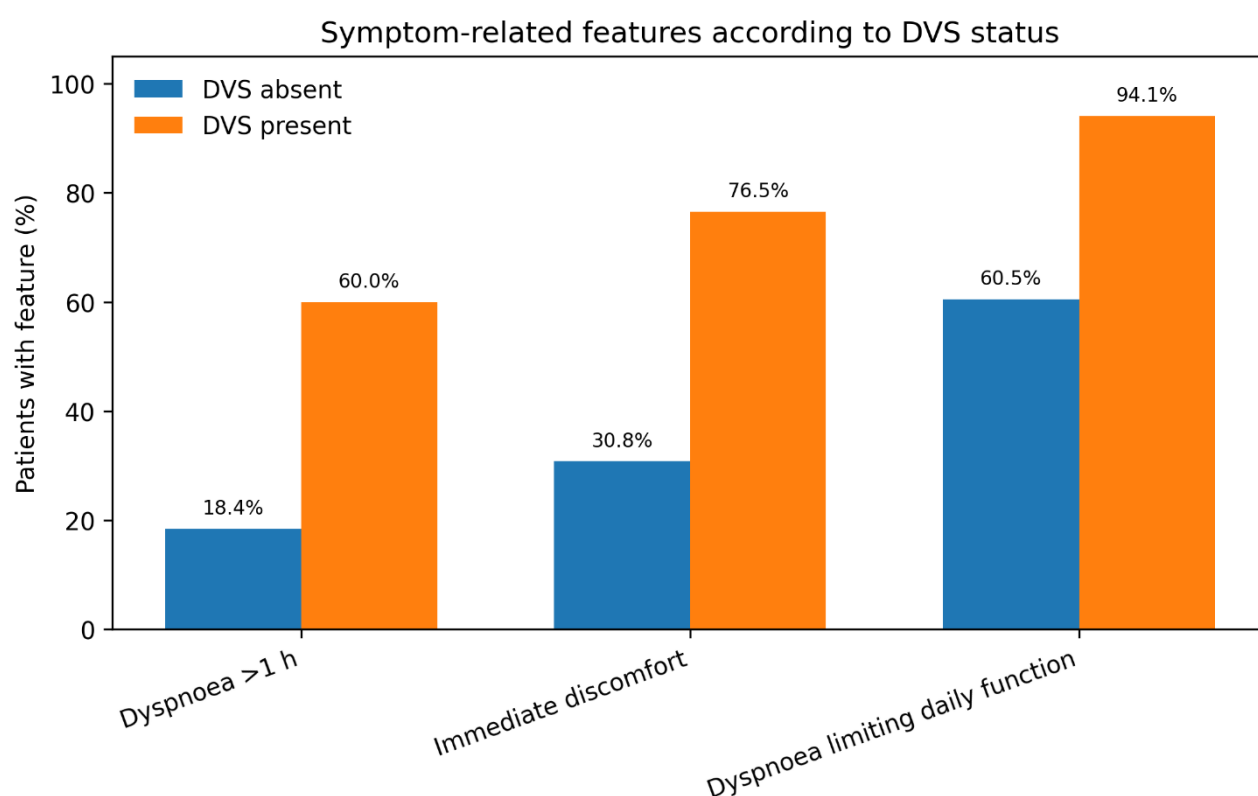


Fig. 2. Symptom-related findings according to deventilation syndrome status. Bars represent the percentage of patients reporting each symptom or functional limitation. DVS – deventilation syndrome; NIV – non-invasive ventilation.

In exploratory univariable logistic regression, achieved driving pressure was associated with higher odds of DVS, with an OR of 1.20 per 1 cmH₂O increase (95% CI 1.02-1.41; $p=0.031$). Achieved IPAP showed a borderline association (OR 1.13 per 1 cmH₂O, 95% CI 1.00-1.28; $p=0.058$), whereas set

driving pressure (OR 1.13 per 1 cmH₂O, 95% CI 0.98-1.31; p=0.097), average daily NIV duration (OR 1.10 per 1 h/day, 95% CI 0.97-1.26; p=0.148), BMI, Mallampati score, CFS, NIV treatment duration, respiratory rate and underlying respiratory diagnosis were not significantly associated with DVS. The key findings are summarised in Table I.

DISCUSSION

The clinical phenotype of DVS in our study was dominated by dyspnoea and discomfort after mask removal. Patients with DVS had substantially higher Borg/VAS scores both immediately after NIV discontinuation and after one hour, and more frequently reported dyspnoea lasting beyond one hour, immediate discomfort after mask removal, and limitation of daily functioning. Although these variables partly overlap with the operational definition of DVS, they indicate that the syndrome represents a clinically symptomatic post-NIV transient state rather than an isolated change in dyspnoea scoring. This is consistent with Schellenberg et al. [4], who reported that more than 90% of patients with DVS experienced the greatest respiratory distress within the first 10 minutes after NIV termination, with gradual improvement over the following hour. Lüthgen et al. [5] similarly observed severe dyspnoea immediately after mask removal, accompanied by transient impairment in vital capacity and exercise tolerance. The temporal pattern observed in our cohort therefore supports the concept of DVS as a post-ventilation transition phenomenon, occurring when the patient moves from assisted to spontaneous breathing.

The most plausible pathophysiological explanation for DVS remains dynamic or NIV-induced hyperinflation. In COPD, expiratory flow limitation, increased airway resistance and loss of elastic recoil predispose to air trapping and static hyperinflation. When ventilatory demand increases or expiratory time becomes insufficient, operating lung volumes may rise further, leading to dynamic hyperinflation, intrinsic PEEP, mechanical disadvantage of the diaphragm and increased work of breathing [7,8]. Several DVS studies support this interpretation. Adler et al. suggested that inappropriate ventilator settings may promote progressive hyperinflation, patient-ventilator asynchrony and unrewarded inspiratory efforts. After PSG-guided ventilator adjustment, pressure support decreased from 13.6 ± 1.8 to 10.3 ± 1.7 cmH₂O, the patient-ventilator asynchrony index decreased from $40.5 \pm 31.0\%$ to $6.7 \pm 7.3\%$, and morning dyspnoea improved from 5.8 ± 2.5 to 2.3 ± 1.6 points [9]. Lüthgen et al. [5] found that patients with DVS had lower inspiratory vital capacity, lower FEV₁, higher effective airway resistance and shorter 6-minute walk distance than controls; immediately after mask removal, both vital capacity and walking distance were transiently reduced and improved over the following hours. Elshof et al. [6] provided further mechanistic support using inspiratory capacity, electrical impedance tomography and diaphragmatic surface

electromyography. In their pilot study, patients with DVS had lower inspiratory capacity than controls both before and after NIV, while diaphragmatic sEMG activity increased after NIV discontinuation, arguing against insufficient neural respiratory drive as the primary mechanism and favouring NIV-induced hyperinflation in patients with pre-existing static hyperinflation.

In our study, achieved driving pressure was significantly higher in patients with DVS in the unadjusted analysis and represented the most relevant non-symptom-related ventilatory signal. This finding is consistent with the hypothesis that excessive pressure support, insufficient expiratory time or patient-ventilator interaction may contribute to post-NIV dyspnoea in susceptible patients. However, this observation should not be interpreted as evidence that lower IPAP is universally preferable. Long-term NIV in chronic hypercapnic COPD is commonly titrated to reduce PaCO₂, and high-intensity NIV strategies may improve gas exchange, dyspnoea, quality of life and selected clinical outcomes in appropriately selected patients [1,2,10,11]. Therefore, the occurrence of DVS should prompt structured reassessment of ventilator settings, including pressure support, expiratory time, trigger sensitivity, leaks, backup rate and patient-ventilator synchrony, rather than automatic reduction of inspiratory pressure.

The role of BMI remains uncertain. Lüthgen et al. [5] reported significantly lower BMI in COPD patients with DVS than in controls, which may reflect an emphysema-predominant phenotype, reduced respiratory reserve or greater respiratory muscle vulnerability. In our cohort, BMI was not associated with DVS. This discrepancy is likely related to differences in study populations. Previous DVS studies were focused on COPD, whereas our cohort included patients ventilated for mixed causes of chronic respiratory failure, including obstructive sleep apnoea and obesity hypoventilation syndrome. Thus, BMI may be a useful phenotypic marker in COPD-specific cohorts, but a less specific predictor in broader home NIV populations. Mallampati score was also not associated with DVS in our study. To our knowledge, Mallampati class has not been systematically evaluated as a DVS risk factor, and current mechanistic hypotheses focus mainly on lower airway mechanics, hyperinflation and patient-ventilator interaction rather than upper airway anatomy.

The clinical significance of DVS lies in its potential effect on daily functioning, treatment tolerance and perceived safety of home NIV. Adler et al. [9] described morning deventilation dyspnoea as a source of considerable discomfort and distress that may influence quality of life and treatment acceptance. Lüthgen et al. [5] reported that one patient discontinued the study because of a panic attack related to severe dyspnoea, while another refused further NIV therapy after being identified as having DVS. These observations do not establish a causal link between DVS and long-

term outcomes, but they suggest that DVS may affect confidence in NIV and willingness to continue treatment. At present, robust data linking DVS with hospitalisation, acute respiratory failure, NIV discontinuation or mortality are lacking, and the long-term consequences of the syndrome remain unclear [5]. In our cohort, the more frequent reporting of dyspnoea-related limitations of daily functioning among patients with DVS supports the clinical relevance of the syndrome, although direct comparison with studies using 6-minute walk distance, CAT or mMRC was not possible because these measures were not included in our dataset.

The therapeutic implications of DVS remain preliminary. Available evidence suggests that selected patients may benefit from optimisation of ventilator settings, particularly when excessive pressure support, inadequate expiratory time or patient-ventilator asynchrony is suspected. In Adler et al. [9], PSG-guided adjustment reduced unrewarded inspiratory efforts and morning dyspnoea without deterioration in nocturnal PtcCO₂ or morning PaCO₂. Mechanical pursed-lips breathing ventilation has also been proposed as a potential strategy. In a retrospective study by Jünger et al. [12], switching patients with advanced COPD and hypercapnic respiratory failure from conventional NIV to pursed-lips breathing ventilation reduced the inspiratory pressure required to maintain capillary pCO₂ and improved 6-minute walk distance and forced vital capacity over a short observation period. Lüthgen et al. [5] also observed reduced morning dyspnoea and improved inspiratory vital capacity after one night of pursed-lips breathing ventilation in patients with DVS. However, these studies were small, exploratory and limited to COPD. Therefore, management of DVS should remain individualised and based on careful reassessment of ventilator efficacy, comfort and synchrony rather than on modification of a single parameter.

Limitations

This study has several limitations. First, the questionnaire-based design precludes causal inference. Second, DVS was defined operationally because no accepted diagnostic standard exists. Third, important mechanistic variables, including body plethysmography (e.g. inspiratory reserve volume and residual volume), spirometry-derived inspiratory capacity, respiratory muscle measurements, nocturnal polysomnography or polygraphy, 6-minute walk distance, COPD Assessment Test and modified Medical Research Council dyspnoea scale were not available due to the fact that the study was conducted among patients in a stable period of the disease, in a home setting. Fourth, the cohort was heterogeneous with respect to the cause of chronic respiratory failure, which increases real-life relevance but may obscure COPD-specific associations such as lower BMI, increased airway resistance or more severe hyperinflation. Further prospective studies

using standardised diagnostic criteria and objective physiological assessment are needed to clarify the mechanisms, clinical consequences and optimal management of DVS.

CONCLUSIONS

Deventilation syndrome was identified in approximately one-third of patients treated with long-term home NIV, indicating that it is a relatively frequent post-NIV symptom complex. DVS was associated with a substantial burden of dyspnoea and discomfort after mask removal, while higher achieved driving pressure emerged as the most relevant ventilatory correlate in this cohort. In contrast, BMI, Mallampati score, frailty, underlying respiratory diagnosis, duration of NIV treatment and respiratory rate were not significantly associated with DVS.

Supplementary material

Supplementary File 1. Patient questionnaire on deventilation syndrome

QUESTIONNAIRE ON THE OCCURRENCE OF DEVENTILATION SYNDROME

IN THE GROUP OF PATIENTS ENROLLED IN THE HOME NONINVASIVE VENTILATION PROGRAM

TO BE COMPLETED BY THE PATIENT WITHOUT THE HELP OF MEDICAL STAFF

PLEASE CIRCLE THE CORRECT ANSWERS

1. Are you currently experiencing shortness of breath (dyspnea)? YES / NO
2. Has shortness of breath ever occurred? YES / NO
3. Shortness of breath occurs: constantly / in episodes
4. Please describe in your own words what symptoms and sensations accompany your shortness of breath:
.....
...
.....
...
5. If shortness of breath has never occurred, please write what symptoms you would consider to be shortness of breath:
.....
...
.....
...
6. Do you feel any discomfort immediately after removing the mask? YES / NO
7. How long does this feeling last?: <5 min, <10 min, <15 min, <20 min, <30 min, <60 min, >60 min
8. Does the shortness of breath / discomfort make it difficult to carry out your daily morning activities? YES / NO
9. Has the shortness of breath / discomfort been present since the start of NIV treatment? If not, how long have you been experiencing shortness of breath / discomfort after removing the mask?
.....
10. Does the type of mask / ventilator settings affect the occurrence of shortness of breath? YES / NO
11. Does shortness of breath occur every time you finish NIV, or only in the morning after a long period of ventilation? Every time / after a long period of ventilation
12. How do you cope with shortness of breath? rest / bronchodilator medication / passive oxygen therapy / oxygen – increased flow / NIV + oxygen / morphine or other sedative medication / cigarette / alcohol
13. Please mark the appropriate answer in the table below regarding the symptoms you experience within one hour after removing the mask following night-time NIV use:

	Always true	Usually true	Sometimes true	Usually untrue	Completely untrue
1. I have problems breathing while eating.	0	1	2	3	4
2. I often suffer from headaches.	0	1	2	3	4
3. I wake up at night due to difficulty breathing.	0	1	2	3	4
4. I am often short of breath.	0	1	2	3	4
5. I have problems breathing while talking.	0	1	2	3	4
6. I often have mucus in my airways.	0	1	2	3	4
7. I have problems breathing during physical exertion.	0	1	2	3	4
8. I am troubled by mask air leaks.	0	1	2	3	4
9. My mask is uncomfortable.	0	1	2	3	4

	Always true	Usually true	Sometimes true	Usually untrue	Completely untrue
10. The ventilator delivers too much air.	0	1	2	3	4
11. I am bothered by dryness in the nose or mouth.	0	1	2	3	4

14. How often does shortness of breath occur (underline one correct answer): constantly every day / several times a week / once a week / several times a month / once a month / once a year / less than once a year / never

15. Do nocturnal episodes of shortness of breath occur: YES / NO

16. Does shortness of breath limit your daily functioning: YES / NO

17. If it does limit it, which activities (you may underline several answers): professional work, practicing sports, leaving the house, performing household activities, sexual activity, Other, please specify...

.....
...

18. Do you experience fear of shortness of breath occurring: YES / NO

19. Education (underline one correct answer): primary / incomplete secondary / complete secondary / vocational / higher

20. Current employment status (underline one correct answer): employed / disability pension / retirement pension / unemployed

21. Housing conditions (underline one correct answer): very good / good / satisfactory / poor

22. Number of people living together in the household:

23. Sexual activity (underline one correct answer): daily / several times a week / once a week / several times a month / once a month / once a year / less than once a year / none

24. Are you aware of the risks / prognosis resulting from the disease that has led to your respiratory failure: YES / NO

25. Are you able to name the medications you are currently taking: YES / NO

26. Please mark the appropriate answer to the questions regarding your symptoms occurring in the evening hours:

	Always true	Usually true	Sometimes true	Usually untrue	Completely untrue
1. I have problems breathing while eating.	0	1	2	3	4
2. I often suffer from headaches.	0	1	2	3	4
3. I wake up at night due to difficulty breathing.	0	1	2	3	4
4. I am often short of breath.	0	1	2	3	4
5. I have problems breathing while talking.	0	1	2	3	4
6. I often have mucus in my airways.	0	1	2	3	4
7. I have problems breathing during physical exertion.	0	1	2	3	4
8. I am troubled by mask air leaks.	0	1	2	3	4
9. My mask is uncomfortable.	0	1	2	3	4
10. The ventilator delivers too much air.	0	1	2	3	4
11. I am bothered by dryness in the nose or mouth.	0	1	2	3	4

27. Duke Activity Status Index (DASI) – referring to the last 1–2 weeks

1. Can you / are you able to take care of yourself, i.e. eat, dress, bathe, or use the toilet? YES / NO

2. Can you / are you able to walk indoors, e.g. around the house? YES / NO

3. Can you / are you able to walk one or two blocks on level ground (approx. 100–200 meters)? YES / NO

4. Can you / are you able to climb stairs or walk up a hill? YES / NO

5. Can you / are you able to run a short distance? YES / NO

6. Can you / are you able to do light housework, such as dusting or washing dishes? YES / NO
7. Can you / are you able to do moderate/light housework, e.g. vacuuming, sweeping floors, or carrying groceries? YES / NO
8. Can you / are you able to do heavy housework, such as scrubbing floors or lifting/moving heavy furniture? YES / NO
9. Can you / are you able to do yard work, such as raking leaves, weeding, or pushing a lawnmower? YES / NO
10. Can you / do you have an active sex life? YES / NO
11. Can you / are you able to take part in moderate recreational activities, such as golf, bowling, dancing, or doubles tennis, or throwing a ball? YES / NO
12. Can you / are you able to take part in strenuous sports, such as swimming, singles tennis, football, basketball, or skiing? YES / NO

28. EQ-5D-5L Health Questionnaire:

Under each heading, please underline the one statement that best describes your health TODAY.

a) MOBILITY

1. I have no problems walking
2. I have slight problems walking
3. I have moderate problems walking
4. I have severe problems walking
5. I am unable to walk

b) SELF-CARE

1. I have no problems washing or dressing myself
2. I have slight problems washing or dressing myself
3. I have moderate problems washing or dressing myself
4. I have severe problems washing or dressing myself
5. I am unable to wash or dress myself

c) USUAL ACTIVITIES (e.g. work, study, housework, family, or leisure activities)

1. I have no problems doing my usual activities
2. I have slight problems doing my usual activities
3. I have moderate problems doing my usual activities
4. I have severe problems doing my usual activities
5. I am unable to do my usual activities

d) PAIN / DISCOMFORT

1. I have no pain or discomfort
2. I have slight pain or discomfort
3. I have moderate pain or discomfort
4. I have severe pain or discomfort
5. I have extreme pain or discomfort

e) ANXIETY / DEPRESSION

1. I am not anxious or depressed
2. I am slightly anxious or depressed
3. I am moderately anxious or depressed

4. I am severely anxious or depressed

5. I am extremely anxious or depressed

29. We would like to know how good or bad your health is TODAY.

This scale is numbered from 0 to 100. 100 means the best health you can imagine. 0 means the worst health you can imagine. Please mark with an X the point on the scale that shows how your health is today. Please write the number you marked in the space provided:

0 _____ 100 (scale from 0 to 100, marked in increments of 10)

30. Assessment of the severity of depression and anxiety – HADS-M scale. Please mark with an X the answer box closest to how you have felt during the past week.

1. I feel tense or wound up: Most of the time / A lot of the time / From time to time / Not at all
2. I still enjoy the things I used to enjoy: Definitely as much / Not quite as much / Only a little / Hardly at all
3. I get a sort of frightened feeling as if something awful is about to happen: Very definitely and quite badly / Yes, but not too badly / A little, but it doesn't worry me / Not at all
4. I can laugh and see the funny side of things: As much as I always could / Not quite so much now / Definitely not so much now / Not at all
5. Worrying thoughts go through my mind: A great deal of the time / A lot of the time / From time to time, but not too often / Only occasionally
6. I feel cheerful, in good spirits: Not at all / Not often / Sometimes / Most of the time
7. I can sit at ease and feel relaxed: Definitely / Usually / Not often / Not at all
8. I feel as if I am in a "psychological slump": All of the time / Very often / From time to time / Not at all
9. I get a sort of frightened feeling like "butterflies" in the stomach: Not at all / Occasionally / Quite often / Very often
10. I have lost interest in my appearance: I have completely lost interest / I am not able to take care of myself / I take about as much care as I should / I take care of myself as much as ever
11. I feel restless, as if I have to be on the move: Very much so / To a large extent / Rarely / I can sit still
12. I look forward with enjoyment to things: As much as I ever did / Less than I used to / Definitely less than usual / Not at all
13. I get sudden feelings of panic: Very often / Quite often / Not very often / Not at all
14. I can enjoy a good book, radio, or TV program: Often / Sometimes / Not often / Very rarely
15. During the past week, it happened that I burst out with anger: Often / Sometimes / Rarely / Not at all
16. It happened that I became irritated or angry: Often / Sometimes / Rarely / Not at all

Thank you for participating in the survey!

QUESTIONNAIRE ON THE OCCURRENCE OF DEVENTILATION SYNDROME

IN THE GROUP OF PATIENTS ENROLLED IN THE HOME NONINVASIVE VENTILATION PROGRAM

**Please conduct the assessment in patients during a stable phase of their disease*

TO BE COMPLETED BY THE PHYSICIAN

PLEASE CIRCLE THE CORRECT ANSWERS

Investigator code (initials) + Center code (first 3 letters of the city) + patient number enrolled in the study:

.....

Date of questionnaire completion:

1. Age (current):

2. Sex: F / M

3. Height [m] (at qualification):

4. Body weight [kg] (at qualification; current):

[Mallampati Score reference image — Class I: complete visualization of the soft palate; Class II: complete visualization of the uvula; Class III: visualization of only the base of the uvula; Class IV: soft palate not visible at all]

5. Mallampati score (1–4):

6. Underlying disease (cause of respiratory failure):

.....

7. Additional (comorbid) diseases:

.....

.....

8. Smoking history:

- Active smoker YES / NO

- Smoking in the past YES / NO

- Passive exposure to tobacco smoke, currently / in the past YES / NO

- Number of pack-years:

9. Date of enrollment in the home noninvasive ventilation program:

.....

10. Ventilation only at night YES / NO

11. Need for NIV use during the day on the patient's own initiative YES / NO

12. Average daily ventilation time [h] in the 1st week of treatment

13. Average daily ventilation time [h] in the week of questionnaire collection

14. Have the ventilator settings been changed since qualification for NIV?: YES / NO

15. Does the patient use NIV alone, or NIV + LTOT (long-term oxygen therapy)?:

.....

16. Oxygen flow [l/min] during qualification and currently during NIV:

.....

17. If oxygen via nasal cannula is required during breaks between NIV sessions, what was the initial flow, and what is it currently?:

18. Humidifier YES / NO

19. Ventilation parameters (average values obtained over the last 24 hours):

INITIAL SETTINGS	
Ventilator make and model:	
Ventilation mode:	
Circuit type: [vented/valved, closed]	
Rise time [ms]:	
Trigger setting [l/min; mbar]:	
Trigger setting, mark [very low, low, medium, high, very high / autoTrack, autoTrack Sensitive] or enter equivalent:	
VALUES OBTAINED	
% of breaths triggered by the patient:	
AHI:	

PARAMETERS		PARAMETERS	
IPAP [cmH ₂ O]		IPAP [cmH ₂ O]	
PS [cmH ₂ O]		PS [cmH ₂ O]	
EPAP [cmH ₂ O]		EPAP [cmH ₂ O]	
RR [breaths/min]		RR [breaths/min]	
Tins. [s]		Tins. [s]	
TV [ml]		TV [ml]	
		I:E	
Oxygen: YES/NO			
Flow [l/min]		FiO ₂	

Modified Borg Scale (in case of inability to cooperate with the patient, the VAS scale may be used) – applies to items 20–23

GRADE	DYSPNEA / FATIGUE
0	Not noticeable
1	Very slight
2	Slight
3	Moderate
4	Somewhat severe
5-6	Severe
7-9	Very severe
10	Maximal

VAS Scale: a 0–10 visual analogue scale from a smiling face (no distress) to a frowning face (worst distress).

20. Degree of dyspnea severity immediately after removing the NIV mask (per modified Borg / VAS scale):

.....

21. Degree of dyspnea severity in the first hour after removing the NIV mask (per modified Borg / VAS scale):

.....

22. Does dyspnea also occur more than 1 hour after the end of ventilation? YES / NO

23. Degree of dyspnea severity in the afternoon, if the patient does not use NIV during the day (per modified Borg / VAS scale):

24. Average oxygen saturation immediately after mask removal [%]:

25. Average oxygen saturation one hour after mask removal [%]:

26. Shortest duration of NIV use [h] after which deventilation symptoms occur:

.....

27. Did morning dyspnea occur before starting NIV treatment? YES / NO

28. Has the physician taken any action in response to the occurrence of deventilation symptoms? YES / NO

29. Were the actions taken effective? YES / NO

30. What actions were taken to reduce dyspnea (more than one answer may be selected):

a) modification of ventilator settings

b) modification of oxygen flow

- c) change of interface (mask)
- d) modification of pharmacotherapy
- e) no action taken

31. Clinical Frailty Scale (CFS) (1–9):

- 1) Very Fit – people who are strong, active, energetic, and motivated. These people commonly exercise regularly. They are among the fittest for their age group.
- 2) Well – people who have no active disease symptoms but are less fit than category 1. They often exercise or are periodically very physically active, e.g. seasonally.
- 3) Managing Well – people with medical problems that are well controlled, but who are not very active beyond routine activities such as walking.
- 4) Vulnerable to Frailty – while not dependent on others for daily living, they often have limited physical activity. A common complaint is being "slowed down" and/or tired during the day.
- 5) Mildly Frail – these people are often noticeably slower and need help with complex activities of daily living (managing household finances, transportation, heavy housework, preparing medications). Frailty typically progresses to impair shopping and walking outside alone, meal preparation, and housework.
- 6) Moderately Frail – people who need help with all outside activities and with keeping house. Indoors, they often have problems with stairs, need help bathing, and may need minimal assistance (support, supervision) with dressing.
- 7) Severely Frail – completely dependent on others for personal care, for whatever reason (physical or cognitive). Nevertheless, they appear to be in a stable condition and not at high risk of dying (within about 6 months).
- 8) Very Severely Frail – completely dependent, approaching the end of life. Typically, they would not recover even from a minor illness.
- 9) Terminally Ill – approaching the end of life. This category applies to people with an estimated life expectancy of less than 6 months, who are not otherwise evidently frail.

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