Chapter 12
Domiciliary Noninvasive Ventilation: Strategies for Improving Adherence to Home Use

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Introduction

Home mechanical ventilation is increasingly used in patients with chronic respiratory failure due to advanced diseases such as chronic obstructive pulmonary disease (COPD), restrictive thoracic disease, and neuromuscular disease (NMD) [1–4]. Home noninvasive ventilation (NIV) may reduce symptoms, improve HRQoL and exercise capacity, and, in many cases, reduce hospitalization and mortality rates [5–8]. Clinicians are well aware of the long-term benefits of home NIV, but they may underestimate the potential human and financial burden of the technological dependency for both patients and caregivers leading to reduced adherence. An analysis of public and private healthcare utilization and costs for NIV in Canada found that median healthcare monthly costs were $3,925, the highest costs being associated with diagnosis of amyotrophic lateral sclerosis and higher levels of dependency [9].

Low Versus High Adherence

Adherence to home NIV decreases the hospitalization rate with an improvement in prognosis when NIV adherence was >5 hours/day, whereas noncompliance leads to complications such as increased hospitalization rate [10, 11]. Therefore, knowledge of reasons for low or lack of adherence is crucial.

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Machine Settings Setting and timing of NIV has been found to influence adherence. In 2014, Borel and colleagues [12] found that spontaneous time mode and night use were more frequent, and inspiratory positive airway pressure values were significantly higher in high-adherence patients (night or daytime use more than 5 hours) than in low-adherence patients with COPD who had been using NIV for at least 1 year. However, there were no differences in hospitalization, emergency department and intensive care unit admission rates, or dyspnea or health status, whereas conjunctivitis was observed more frequently in the high-compliance group [12], suggesting that adherence does not necessarily significantly impact on health status.

Intelligent volume-assured pressure support (iVAPS) is a hybrid mode of servoventilation, providing constant automatic adjustment of pressure support ventilation (PSV) to achieve a target ventilation according to the patient's ventilatory requirements. iVAPS was as effective as PSV initiated by a skilled healthcare professional in controlling nocturnal hypoventilation and produced better overnight adherence in patients naive to NIV [13]. However, a recent meta-analysis shows that there is no significant difference in clinical outcomes and compliance when comparing iVAPS support and PSV [14]. Noninvasive ventilation settings determined during wakefulness may produce patient-ventilator asynchrony during sleep, causing sleep disruption and limiting tolerance. A study found that NIV titrated with polysomnography was associated with less patient-ventilator asynchronies but not less sleep disruption or better adherence when compared to therapy titrated during daytime alone [15]. The use of the nasal mask was associated with better adherence as compared to the use of the oronasal mask [16].

Demographics and Anthropometrics Patients with obstructive sleep apnea (OSA) under continuous positive airway pressure (CPAP) with poor adherence (use of device <4.5 hours per night) after 1 year of treatment were significantly younger, had higher body mass index (BMI), and required more unscheduled visits during the first year. After 12 months, dropouts were observed only among patients with poor adherence and were significantly more frequent during the first 5 years [16].

Other Factors Dry mouth, mask incompatibility, and gastrointestinal complaints have also been found to negatively influence adherence [12]. A study evaluated the compliance with NIV in patients with myotonic dystrophy type 1 and identified predictors of cessation at 5 years [17]. Compliance during the first year was higher when symptoms of respiratory failure were initially present and lower in the case of acute respiratory failure. Long-term compliance was associated with symptoms of respiratory failure and nocturnal arterial oxygen desaturation. Cessation was more frequent in the cases of excessive leaks, ventilator dysfunction requiring emergency technical intervention, or high BMI. Cessation was less frequent for patients with a professional occupation or undergoing professional training [17].

Table 12.1 Key factors for discharge plans to home with NIV

Decision-making	Appropriate information of patient and caregiver
Feasibility	Appropriate location
Education and training	Self-care
Needs	Balance between needs and resources
Follow-up	Role of stakeholders
Risk management	Minimization

Discharging Patients on Home NIV

Risks for reduced or lack of adherence to NIV programs may be avoided or decreased by the early use of discharge plans, when the appropriate setting of ventilation has been prescribed, together with the beginning of educational sessions [18]. A comprehensible and simple plan should include needs, wishes, and activities of all persons and institutions involved, such as patients, caregivers, and other stakeholders. This requires the collaboration among patients and their family members, professional caregivers, prescribing centers, provider companies, third-party payers, and other stakeholders, avoiding discrepancies between prescribing centers and the management in the home setting [19–22]. Table 12.1 shows the key elements in discharge planning [23].

A survey has shown that formal teaching of relevant knowledge and skills within the hospital setting prior to discharge had an immediate and long-lasting positive impact [24]. However, conflicts between families and professionals, information gaps, and persistent lack of trained caregivers at home were problems. Participants strongly recommended improved transitional care such as telephone support from respiratory health professionals, home outreach, in addition to training of caregivers [24].

Education

Education programs for patients and caregivers should be well structured, goal directed, and competence based with clear learning outcomes, aimed to the specific needs of individual patients and caregivers, respecting their willingness and autonomy. Theoretical and practical sessions are required (see Chap. 3). The specific knowledge and skills should be verified periodically in order to ensure that the caregiver (and the patient, when able) has acquired and still maintains the necessary abilities. Refreshment sessions should be provided when needed, dealing with equipment, potential problems and possible solutions, technical aspects such as ventilator type and setting, interfaces (different masks), day/nighttime of ventilatory support, and caregivers (professional vs relatives).

Table 12.2 Basic theoretical knowledge required by patients and caregivers

Anatomy and physiology of the airways
Working principles of the specific patient's ventilator
Appropriate humidification when applicable
Choice of masks: the importance of minimizing leaks and of transparency of material
Side effects
Risks of accidental disconnection from the ventilator

Table 12.3 Practical skills required by patients and caregivers to manage domiciliary NIV [26]

Positioning of the mask, selection of headgear and the proper tightening to prevent or minimize leaks, and pressure on the face
Airway clearance techniques
Recognition of signs of infections
Hygienic precautions when dealing with the ventilator, masks, circuits, humidifiers, and disposables
Understanding ventilator settings and troubleshooting, alarms, and related action
Assemble and disassemble relevant equipment, such as masks, the ventilator circuit, and the humidifier
Whom to call, and what to do, in an emergency
Resuscitation skills are sometimes included

Attention should be paid also to the workload and working conditions of caregivers, especially family members, including mental and emotional stress. Indeed, most caregivers of chronically critically ill patients report high levels of depressive symptoms, persisting up to 1 year and not decreasing in some caregivers [25]. Tables 12.2 and 12.3 show the minimal theoretical knowledge and the practical skills required by patients and caregivers [26]. However, currently organized training in NIV even for professionals is implemented only in a few developed countries [27].

Safety

Mechanical malfunctions of ventilators are rare in home NIV; however, mistakes in interaction between the user/caregiver and the ventilator may lead to problems, and therefore, risk management is an important aspect of home ventilation strategies. Monitoring is crucial for effectiveness of, and adherence to, ventilation, prevention of potential adverse effects, improvement of patient/caregiver training, maintenance of equipment, and resetting of ventilator settings according to the changing conditions of the patient [28].

Periodic clinical assessment is very useful, looking for improvements in nocturnal hypoventilation symptoms, sleep quality, and side effects, major cause of lack of adherence. Screening side effects may lead to the need to change the interface, gas humidification, or ventilator settings. Home care providers should maintain ventilator and interface, and also educate patients for correct use. Assessment of arterial blood gases may show significant improvement of hypercapnia when NIV is efficient or reveal worsening when application has not yet been optimized. Analysis of ventilator data may reveal daily use, unintentional leaks, upper airway obstruction, or patient-ventilator synchronies. Nocturnal oximetry and capnography are additional monitoring tools to assess the impact of NIV on gas exchanges [28]. Table 12.4 shows some common issues to monitor or periodically check.

Quality control of the equipment is necessary in order to ensure that patients safely and accurately receive the prescribed and required ventilatory support. An early survey [29] covering 16 European countries providing home mechanical ventilation to more than 20,000 patients showed with relevant inter- and intracountry differences that:

- The ventilator service was mainly carried out by external companies, with a frequency ranging 3–12 months.
- The interaction between companies and prescribers was limited.
- The participation of centers in equipment quality control was poor.

Patients under home NIV have a substantial requirement for assistance, but most technical problems can be resolved simply. Where no fault in equipment can be found during a check, the patient himself may have mistaken clinical deterioration for an equipment problem and should receive early clinical evaluation. This was shown by a report on the nature of calls to a home support helpline for more than 1,000 adult and pediatric patients on home ventilation [30]. There were more than 500 daytime and 10 nighttime calls per month. Home visits identified technical problems potentially fixable in 64% or required replacement or new parts of devices in 22% of cases. Rather interestingly, out of calls without any identified mechanical fault, half of patients were either found to be unwell or even required hospital admission [30].

Table 12.4 Common issues to monitor or periodically check

Clinical status
Mask condition
Ventilator setting
Arterial blood gases
Unintentional leaks
Patient-ventilator synchrony
Night pulse oximetry
Capnography

Tele-monitoring

The situation may be far more challenging if the patient lives in a regional location, a substantial distance from expert health centers. This may explain the growing interest in the development of tele-monitoring systems [31–35].

Starting and monitoring long-term NIV in an outpatient setting has been shown to be safe and feasible although without any clinical advantage as compared to usual care [36]. However, the use of tele-monitoring to adapt patients to home ventilation showed a reduction in healthcare resources consumption with clinical results and levels of adherence similar to in-hospital settings [37]. A randomized controlled trial of tele-assistance program for patients with chronic respiratory failure including COPD resulted in reduction in hospital admissions, general practitioner calls, and costs [35]. In a retrospective study, a tele-assistance program alone reduced the exacerbations rate of patients on long-term oxygen therapy, with greater effectiveness, when added to long-term NIV [38].

Information and communication technologies applied to healthcare and advances in sensor and data transmission technology allow tele-medicine-based programs. New sensors, transmission devices, and interventions have been developed to allow technology to support home care in new ways [31, 33, 39]. Ventilator data downloads, via early remote assessment, can help optimize patient ventilation through identification of modifiable factors, in particular, interface leak and ventilator prescriptions [40].

However, the acceptance of these systems by patients is not guaranteed. A recent survey on home ventilator users' perception of care provision across Europe [41] reported that only about half of respondent patients would be confident with a tele-monitoring system of their program. Unfortunately, another international survey on patterns of home NIV use in COPD patients reported that tele-medicine was only an option for 5% of respondents [42].

Practical Recommendations

On the basis of historical experience, several practical recommendations on NIV have been proposed, which may serve as an indication to proper use [20, 21, 43].

- Home NIV must be prescribed and organized in an experienced and authorized center, and the treating healthcare professional should be responsible for the organization of home care.
- Adaptation to NIV in the ambulatory setting is not inferior to hospital adaptation in terms of therapeutic equivalence in stable patients with chronic respiratory failure [15, 44, 45].
- The targets of program must be defined and clearly explained to the patient.

- Costs and supply of equipment, resources, and materials must be defined before discharge. Patients and caregivers must be instructed and must demonstrate that they know how to perform home NIV.
- In COPD patients with chronic hypercapnia, NIV is effective in improving arterial blood gases and in unloading inspiratory muscles independent of whether it is set on the basis of patient comfort and improvement in arterial blood gases or tailored to patients' respiratory muscle effort and mechanics [46].
- Appropriate application of expiratory positive airway pressure (EPAP) can abolish end-expiratory flow limitation and alleviate the intrinsic positive end-expiratory pressure, to reduce work of breathing and inspiratory triggering asynchronies [47].
- Auto-titrating modes of NIV providing variable support during changes in respiratory loads through sleep stages and disease progression may lead to enhanced clinical outcomes [48].
- Preliminary studies indicate that pressure–volume NIV combined with auto-titration of EPAP might be effective in reducing upper airway obstruction and in maintaining clinical stability in patients with COPD–OSA overlap, improving sleep comfort and compliance. Such modes of ventilation could be utilized to facilitate an outpatient setup [49].
- Changes to the ventilator or ventilator settings should always be performed under clinical conditions, with arterial blood gases and expert assessment of the patient [19]. Identically built machines with the same settings can be exchanged outside the hospital, whereas different machines must be exchanged under hospital conditions in the center for NIV [50].
- A humidifier, mandatory for invasive ventilation, may be also useful for NIV if typical symptoms are present [51].
- A number of masks each year must be agreed with the healthcare professional at the time of prescription. Each patient requires at least one reserve mask.
- Patients with NMD and weak or insufficient cough and children should be provided with a pulse oximeter and cough-supporting machines.
- The first follow-up visit must occur in the short term (4–8 weeks), and therapeutic success should be evaluated according to predefined subjective, clinical, and technically measurable parameters.
- The equipment provider must guarantee round-the-clock availability and ensure a prompt and customized service (including back-up and "switch out" ventilators, processes for rapid admission, etc.).
- Nutrition is a common problem in patients with chronic respiratory failure; therefore, it is a key component in the long-term management. As home ventilation is usually prescribed in end-stage respiratory disease patients with poor nutritional status, nutrition and dietary intake-related problems need to be carefully assessed and corrected [52].
- Patient-centered outcomes are significantly modified by home NIV, and we need short, self-administered, specific tool for routine clinical assessment [53].

Conclusion

The aim of home NIV is to sustain breathing and when possible a self-managed life in patients with severe chronic respiratory failure. The responsibilities of patients, caregivers, and health care professionals should be defined.

Key Messages

- Discharge planning is an evolving process according to changes in circumstances.
- Be proactive and identify in advance unique needs of patients and caregivers.
- Training of caregivers should be well structured, goal directed, and competence based.
- Teamwork and coordination of multiple stakeholders are the core issue of discharge to home noninvasive ventilation.
- An individualized package of care should be designed, with the agreement of the patient and caregivers, and this must be appropriate to their local situation.

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