The role of telemonitoring in patients on home mechanical ventilation

Ries van den Biggelaar[1], Anda Hazenberg [2,3] and Marieke L. Duiverman [2,3]

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Edited by Leo Heunks and Marieke L. Duiverman

[1]Dept of Pulmonary Diseases/Home Mechanical Ventilation, Erasmus University Medical Center, Rotterdam, The Netherlands. [2]Dept of Pulmonary Diseases/Home Mechanical Ventilation, University of Groningen, University Medical Center Groningen, Groningen, The Netherlands. [3]Groningen Research Institute for Asthma and COPD (GRIAC), University of Groningen, University Medical Center Groningen, Groningen, The Netherlands.

Corresponding author: Marieke L. Duiverman (m.l.duiverman@umcg.nl)

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Telemonitoring is a promising method to improve home mechanical ventilation care, both during initiation and the follow-up period. https://bit.ly/3BL5s2G

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Abstract

There is a growing number of patients being treated with long-term home mechanical ventilation (HMV). This poses a challenge for the healthcare system because in-hospital resources are decreasing. The application of digital health to assist HMV care might help. In this narrative review we discuss the evidence for using telemonitoring to assist in initiation and follow-up of patients on long-term HMV. We also give an overview of available technology and discuss which parameters can be measured and how often this should be done. To get a telemonitoring solution implemented in clinical practice is often complex; we discuss which factors contribute to that. We discuss patients' opinions regarding the use of telemonitoring in HMV. Finally, future perspectives for this rapidly growing and evolving field will be discussed.

Introduction

The number of patients with chronic respiratory failure needing home mechanical ventilation (HMV) is increasing. In the Eurovent analysis, published in 2005, the estimated prevalence of HMV in Europe ranged from 0.1 to 6.6 per 100 000 people [1]; however, more recent data showed prevalence ranging from 3.9 per 100 000 inhabitants in Hungary [2] and up to 63 per 100 000 inhabitants in Italy [3]. In well-described cohorts, it has been shown that HMV use has substantially increased since 2000 [4, 5]. Furthermore, diagnostic categories have changed over the years. In many centres HMV was initially mainly used in patients with neuromuscular diseases (NMDs). More recently, the use of home noninvasive ventilation (NIV) has grown substantially in patients with obesity hypoventilation syndrome (OHS) and chronic obstructive pulmonary disease (COPD) [4]. The prevalence of paediatric HMV has also increased, and more ventilator-dependent children are transitioning to adult care [6].

With increasing patient numbers, changing disease categories and increasing complexity of diseases, alongside changing rules and regulations in healthcare and healthcare resource limitations, HMV care is becoming more challenging. To make this complex treatment successful, now and in the future, patients need to be carefully and extensively monitored, trained and supported, and data need to be collected to drive research and improve future care. Despite its complexity, there are several reasons why these acts of monitoring and support are preferably provided at home. First, patients prefer home support of their therapy, which is by nature carried out at home. Second, in-hospital resources for elective chronic care are decreasing. During the recent COVID-19 pandemic, many HMV centres experienced severe problems in initiating HMV promptly and in delivering regular follow-up. To overcome these challenges, the use of information and communication technologies for health service delivery, so-called telemedicine, holds great promise for the future of HMV [7].

"A Europe fit for a digital age" is one of the six political priorities of the European Commission 2019–2024 [8]. In the field of HMV, digital health might also improve access to this treatment in areas with fewer hospital resources and might improve the quality of ventilatory support and care in the most efficient way. Ideally, telemedicine would lead to less inpatient hospital care, less healthcare consumption, lower costs and a more patient-centred approach.

In 2016, a European Respiratory Society (ERS) Task Force developed a statement on telemonitoring of ventilator-dependent patients which the aim of describing commonly accepted indications, follow-up schedules, equipment and facilities and legal issues [9]. However, since then, the field has progressed. In this narrative review we aim to discuss the literature on telemonitoring in HMV initiation and follow-up as well as challenges that are encountered regarding ways of telemonitoring, available technology and the implementation of telemonitoring in HMV care. Also, patients' opinions will be discussed. We aim to provide guidance to clinicians working with or starting telemonitoring in HMV care.

Initiation of chronic NIV at home with the use of telemonitoring

Historically, in many institutions chronic HMV routinely started in a clinical setting, requiring several days and up to a week of hospitalisation. However, in-hospital initiation of chronic care has several disadvantages. First, hospital admission is often stressful and an emotional burden for patients. Second, being admitted to the hospital increases the risk of developing a nosocomial infection. Third, in many countries, healthcare resources are becoming depleted and hospital beds are required for acute care, as became clear during the COVID pandemic. It is intuitive that the costs of starting HMV in a hospital setting are higher than the costs of starting at home. Therefore, a change in the way chronic HMV is initiated and delivered is required.

Studies have been performed showing that at-home initiation of chronic NIV in patients with NMDs, thoracic restrictive disease and COPD combined with the use of telemonitoring of ventilator data, transcutaneous measured gas exchange parameters and daily nurse-led adjustments of ventilator settings is noninferior to in-hospital initiation [10–12]. Furthermore, compared to several days of in-hospital initiation, direct costs of this way of working were considerably lower.

Although these studies resulted in a change in practice in the Netherlands, the NIV set-up in these studies with extensive telemonitoring is a topic of debate. Time spent by healthcare professionals in initiating NIV increased compared to the in-hospital service, meaning the process was not necessarily more efficient. Technological issues, such as bugs in the transfer of data and lack of synchronisation of data, required additional home visits and decreased efficiency. Furthermore, the comparator of home initiation was standard care in-hospital initiation of 5–7 days, a practice that is uncommon in other countries, where initiation of long-term NIV is performed in an outpatient setting [13] or with just 1–2 nights of in-hospital acclimatisation [14]. Overall, interesting questions have risen regarding the procedure, *e.g* can (part of) the initiation process be performed at the outpatient clinic, what monitoring parameters are minimally needed to optimise NIV, and are automatic modes useful to adjust ventilator settings automatically at home?

In some patient groups, outpatient set-up of chronic HMV (without telemonitoring) is feasible and effective, even without nocturnal monitoring [13, 15]. However, getting used to the ventilator and mask often requires repeated training sessions supervised by a professional, especially in patients who need higher settings or in patients with bulbar disease [15]. In the study of Luján *et al*. [16], adaptation at the outpatient clinic was an effective alternative for in-hospital adaptation, although it still required 5.5 days and there was, in this study, an opportunity to check ventilation by performing arterial blood gases, also at home. A recent randomised controlled trial in patients with amyotrophic lateral sclerosis (ALS) compared a protocol of outpatient acclimatisation of a minimum of eight 2-h sessions with a protocol of home acclimatisation (without telemonitoring) of a minimum of eight 2-h sessions. This study found that 38% of the outpatient acclimatisation and 29% of the home acclimatisation groups required more than eight sessions to get sufficiently used to the ventilator. Outcomes were comparable; interestingly, the home acclimatisation group was, after the initiation period, more satisfied with the delivered care and scored higher on the general health subscore for quality of life [17]. This study was performed in patients living within 40 km of the hospital. In our experience, travelling to the hospital is often very complicated and being at the hospital very stressful for patients who are severely disabled by their disease; therefore, from a patient perspective we strive to acclimatise patients at home instead of at the outpatient clinic. For patients with less severe disease, using, *e.g.*, 1 day outpatient acclimatisation and mask fitting with several days of nocturnal home telemonitoring combined with video consultations might provide a good balance between efficiency and efficacy [18].

Which parameters need be monitored for successful NIV initiation is a topic of debate. First, data collected by the ventilator *e.g.* usage, leakage and apnoea/hypopnea indices, can be monitored. By inspecting breath-by-breath flow and pressure curves, one can have a detailed view on the way the patient and the ventilator are collaborating (so-called patient–ventilator synchrony/asynchrony (PVA)) [19]. PVA data are thus available from ventilator readings, without the need for additional monitoring equipment, although some PVAs remain undetected [20]. However, online platforms now seldomly supply healthcare professionals with pressure and flow curves, so these data are often unavailable remotely. Moreover, it is currently unknown how ventilator data and PVA relate to clinical outcomes [21]. Optimal ventilation in terms of applied pressures, optimal synchrony or by fixing minimum tidal or minute volumes delivered (as with volume-assured modes) does not ensure that effective alveolar ventilation and correction of hypoventilation are achieved. Particularly in patients with lung diseases, high dead-space ventilation and ventilation–perfusion mismatching might alter the effect of NIV on gas exchange. Therefore, we advocate the monitoring of gas exchange, at least once the ventilator has been set comfortably and optimally, to ensure that hypoventilation is indeed corrected optimally. This should preferably also include nocturnal data because daytime gas exchange might be misleading; neuromuscular patients who are normocapnic during the day might hypoventilate during the night [18] and *vice versa* COPD patients who are effectively ventilated during the night might become hypercapnic during the day. Remote monitoring of additional parameters reflecting effect (reduced hypercapnia and work of breathing, improved sleep quality and/or symptoms) is more complex because this often requires standalone monitoring, with no technology for remote monitoring through the ventilator connection, or separately through connection to an online platform. Nevertheless, monitoring effect is of utmost importance, *e.g.* chronic NIV is known to have clinical benefit in COPD because settings have been found that achieve improvement in gas exchange [22, 23]. Ideally, there should be time synchronised monitoring of both ventilator data and data reflecting NIV effectiveness. Although several steps need to be taken, there has been progress, connecting, for example, oximetry, transcutaneous monitoring of gas exchange and polysomnographic monitoring to some ventilators, allowing synchronous monitoring of ventilator data and "outcome" data.

Finally, a recent study showed that automatic titration of NIV completely at home using average volume-assured pressure support-automated expiratory positive airway pressure (AVAPS-AE) (without telemonitoring) in patients with OHS with or without obstructive sleep apnoea was not necessarily more cost-effective than inpatient titration at the clinic [24]. This was mainly due to an increase in unplanned visits to healthcare professionals in patients in the home automatic titration group. Although no differences were found in outcomes like partial arterial carbon dioxide pressure and health-related quality of life (HRQoL) after 3 months between the groups, this increased acute healthcare requirement might relate to the more complex automatic mode or suggest that patients feel less confident after unsupervised at-home titration of NIV.

Follow-up of chronic NIV at home with the use of telemonitoring

The reason for follow-up in a patient with HMV is to ensure effective, comfortable and safe use of a ventilator. In most centres, follow-up of HMV was or is still performed through regular visits to the outpatient clinic [25] or inpatient measurements [26] of sleep quality and nocturnal gas exchange. During follow-up visits, symptoms are noted, ventilator data can be read and gas exchange can be checked, either through blood gas analysis or by nocturnal gas exchange monitoring, in the hospital or at home. However, travel to the clinic is often a burden for ventilator-dependent patients and travel time might be prolonged because of the centralisation of HMV care. Also, patients have been hesitant to visit the hospital owing to the fear of becoming infected with corona (or other) respiratory viruses. Follow-up of patients is thus at arbitrarily chosen intervals and deteriorations might be missed. Remote monitoring provides the opportunity to monitor more frequently or even continuously, combining different sources of monitoring without the additional burden for the patient of travelling to the hospital.

Despite these theoretical advantages, telemonitoring for the follow-up of HMV is still an upcoming field with different challenges. Literature on the added value of telemonitoring for the follow-up of patients with chronic respiratory failure is mainly descriptive; papers have described observational cohorts [27–32], case descriptions [33–35], case-controlled studies [36] or nonrandomised studies [37] (table 1). Therefore, except for showing that telemonitoring is feasible, it is difficult to judge (non)-inferiority or even added

TABLE 1 Summary of important studies investigating telemonitoring for the follow-up of patients on HMV

Study	Design	Population	E-health intervention	Duration	Outcomes
Controlled studies					
Vitacca *et al.* 2009 [38]	Randomised clinical trial	Patients with chronic respiratory failure N=240 (COPD n=101, restrictive n=28, NMD n=50, ALS n=22, other n=19)	**Telemonitoring and teleconsulting** TA: pulse oximetry with modem, data can be sent to a TA nurse for real-time teleconsultation, unscheduled calls transferred to an on-duty pulmonologist for a consult	1 year, TA on demand	Compared with controls, TA group experienced significantly fewer hospitalisations (−36%), urgent GP calls (−65%) and acute exacerbations (−71%) COPD patients had fewer hospitalisations, ED admissions, urgent GP calls or exacerbations After deduction of TA costs, the average overall cost for each patient was 33% less than that for usual care
Pinto *et al.* 2010 [37]	Prospective, single-blinded controlled trial Patients assigned according to their residential area to a control group (G1, patients living in Lisbon, ventilator parameters readout during office visits) or an intervention group (G2, patients living outside Lisbon, received a modem connected to the ventilator)	40 patients on HMV with an underlying diagnosis of ALS	**Telemonitoring, teleconsulting and tele-adaptations** Telemonitoring group had a modem installed at home for at least weekly communication Communication protocol was bidirectional so adjustments to the ventilator settings were permitted and evaluated directly Home visit, outpatient clinic visit or phone calls could be planned, depending on the patient's clinical situation	From NIV initiation, a period of 3 years of follow-up or death	FVC was higher in G1 at diagnosis No difference in compliance was found between the groups The incidence of changes in parameter settings throughout the survival period with NIV was lower in G2 ($p<0.0001$) but it was increased during the initial period needed to achieve full compliance Number of office or ED visits and in-hospital admissions were significantly lower in G2 ($p<0.0001$) Survival showed a trend favouring G2 ($p=0.13$)
Chatwin *et al.* 2016 [39]	Randomised crossover trial	Patients with chronic respiratory failure N=72 (COPD n=39, other diagnoses n=33) NIV in 52% and LTOT in 63%	**Telemonitoring and teleconsulting** Daily: Heart rate, finger pulse oximeter, and questionnaire on breathlessness, wheeze, sputum production, sleep quality and therapy alterations Weekly: Weight, blood pressure Philips Motiva system	1 year (6 months *versus* 6 months)	No difference in median (IQR) days to admission between the two groups (telemonitoring: 77 days (IQR 114 days); control: 77.5 days (IQR 61 days); p=0.189) Hospital admission rate at 6 months increased (telemonitoring: 0.63; control: 0.32; p=0.026) Home visits increased during telemonitoring, GP consultations were unchanged Self-efficacy fell, while HADS score improved marginally during telemonitoring

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TABLE 1 Continued

Study	Design	Population	E-health intervention	Duration	Outcomes
Vitacca *et al.* 2016 [40]	Retrospective study (based on patient selection from Vitacca *et al.* 2009 [38])	Hypercapnic COPD patients on LTOT therapy that could be combined with NIV	**Telemonitoring and teleconsulting** Comparison between four groups Group 1: LTOT Group 2: LTOT+NIV Group 3: LTOT+TA Group 4: LTOT+NIV+TA	1 year, TA on demand	Risk of exacerbation statistically different among groups (p=0.0002) TA addition to NIV significantly reduced exacerbation risk when compared with that of all groups Hospitalisation risk was statistically different among groups (p=0.049) Addition of TA to LTOT but not to NIV significantly reduced hospitalisation risk when compared to Group 1 (p=0.013) Risk of mortality did not differ among groups (p=0.074)
Trucco *et al.* 2018 [36]	2-year longitudinal multicentre case-controlled trial	Adolescent ventilated patients with underlying NMD (N=48), mean age of 16.4 years	**Telemonitoring and teleconsulting** Weekly arterial oxygen saturation, heart rate and ventilation parameters uploaded Deviations in clinical conditions or parameters led to the patient being contacted and necessary measures taken	2 years	Exacerbations in telemonitoring patients did not differ from controls (59 *versus* 53; p=0.15) Hospitalisations were significantly reduced in telemonitoring patients compared with those prior to telemonitoring (11 *versus* 24, p=0.04) and to controls (11 *versus* 21, p=0.03) Median hospitalisation length was significantly lower in telemonitoring patients than controls (6 *versus* 7 days, p=0.03) Caregivers' satisfaction was excellent whereas no significant changes in Caregiver Burden Inventory were seen (32.5 *versus* 35.5, p=0.06)
Leonard *et al.* 2021 [41]	Randomised controlled trial	20 COPD patients admitted with AECOPD and with >2 admissions in the previous year	**Teleconsulting** NIV *versus* NIV+TA TA: Telephone calls by call centre; structured questionnaire about symptoms, inhaler and NIV use Predetermined workflow Daily calls first week after discharge; every other day for week 2; then every third day	3 months	4 of 20 patients did not use NIV Remaining patients used the NIV on 35% of the nights (49% of the nights; 3.1 h·night^{-1} in the NIV+TA *versus* 15% of the nights, 1.0 h·night^{-1} in the NIV-only group)

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TABLE 1 Continued

Study	Design	Population	E-health intervention	Duration	Outcomes
Baltaxe *et al.* 2020 [42]	Randomised controlled trial	67 adults on NIV	**Teleconsulting** Intervention: face-to-face motivational intervention by a psychologist followed by daily reporting of use and problems with NIV on a mobile app followed by a generated advice Control: usual care	3 months	No changes in adherence or self-efficacy Patients scored the perception of continuity of care and person-centred care as high
Observational non-controlled studies					
Zamith *et al.* 2009 [29]	9-month observational study	44 patients with chronic respiratory failure (total 51 patients)	**Telemonitoring** Daily: peak expiratory flow rate, oximetry, ECG, heart rate, compliance of LTOT and NIV treatment, rescue medication, respiratory symptoms, sleep quality, smoking Weekly: QoL questionnaire, mobility questions, monthly weight	9 months	80% reported problems with the equipment Reduced number and duration of hospital admissions Improved HRQoL 80% reported they were more/much more supported, 75% would use this system in the future
Bertini *et al.* 2012 [27]	2-year observational study	Ondine syndrome/COPD/MD/ chest wall deformities/ALS N=16	**Telemonitoring and teleconsulting** Once weekly nocturnal monitoring of ventilator parameters and S_{aO_2} during HMV that was transmitted to respiratory intensive care doctor Telephone counselling	1 year	9 of 16 patients showed good compliance to the study protocol and 7 of 16 showed poor compliance Mean number of connections was 46.12 for the total group and 63.8 for the patients with good compliance 8 patients made an urgent call to the respiratory intensive care doctor, and due to the available information and following actions in 5 of 8 cases a visit to the ED was not necessary
Garuti *et al.* 2013 [28]	Prospective observational study	Neuromuscular patients N=13 (n=10 with HMV, of which 5 with tracheotomy)	**Telemonitoring and teleconsulting** Daily registration of signs and symptoms and pulse oximeter Pulmonologist set the indication for intervention using chest physiotherapy	2 years	23 alerts transmitted to the pulmonologist 241 respiratory therapist interventions

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TABLE 1 Continued

Study	Design	Population	E-health intervention	Duration	Outcomes
Onofri *et al.* 2020 [30]	Descriptive retrospective design	Children (N=21) on NIV of IMV	**Telemonitoring and teleconsulting** Comparison between telemonitoring (n=8) and non-telemonitoring (n=13)	3 months	12 healthcare problems detected, only one problem could not be solved by remote intervention
Thomas *et al.* 2021 [31]	Prospective pilot study	Children (N=57), median age of 13 years, with OSA, nocturnal hypoventilation or both	**Telemonitoring and teleconsulting** Data collection on ventilator parameters combined with parent contact on days 14, 42 and 90 after initiation of HMV Based on the information any problems were resolved	90 days	Median nightly usage decreased in Week 1 (6.92 h) *versus* Week 12 (6.15 h), p=0.04 Mask leak was higher in Week 1 (17.7 L·min^{-1}) *versus* Week 12 (14.7 L·min^{-1}), p=0.053 No significant difference in AHI between Week 1 (2.7·h^{-1}) *versus* Week 12 (2.3·h^{-1}), p=0.75 45% of respondents felt active remote monitoring positively influenced PAP usage
Tran *et al.* 2021 [34]	Descriptive case series	Children (N=3)	**Teleconsulting** Measurements of the face performed by family caregiver with guidance of respiratory therapist Mask selection performed by a member of the long-term ventilation team	NA	Virtual/telemedicine programme to manage paediatric patients requiring mask fitting for long-term ventilation was a feasible option during COVID-19 (conclusion from abstract)
Zamarrón *et al.* 2014 [35]	Descriptive case series	Patients with NMD (N=3)	**Telemonitoring and teleconsulting** Videoconferencing and telemonitoring of cardiorespiratory variables (oxygen saturation, heart rate, blood pressure and ECG)	5 years	Number of hospital admissions and hospital consultations fell after enrolment in the telemedicine programme
Portaro *et al.* 2018 [33]	Prospective study	4 siblings with facio-scapulo-humeral muscular dystrophy with respiratory failure	**Telemonitoring, teleconsulting and telerehabilitation** 1. Videoconferencing (once a week) 2. Telemonitoring of cardiorespiratory variables (3 times a day) 3. Telerehabilitation with respiratory physiotherapy (twice a week)	6 months	540 videoconferences per patient including 3 daily contacts Hospital alarms activated 45 times but not clinically relevant 20 exacerbations associated with infectious disease which required pharmacological therapy, but no hospital admissions

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TABLE 1 Continued

Study	Design	Population	E-health intervention	Duration	Outcomes
Cantarini *et al.* 2022 [43]	Prospective cohort	34 selected patients in the "Home Doctor" telemonitoring programme 82% IMV	**Telemonitoring** Ventilator parameters and settings analysed by a clinical physical therapist 3 times per week; interventions if needed	3 months	50% of patients were provided optimisations of their HMV Reductions in extra clinical visits and in device problems Telemonitoring promoted a feeling of enhanced wellbeing and safety
Muñoz-Bonet *et al.* 2020 [32]	Prospective cohort	12 children on IMV	Big Data telemedicine home system	2 years	11 of 141 detected events required hospitalisation 38 hospitalisations were avoided All the families considered that telemedicine had helped to avoid hospital visits, was not an intrusion into their privacy, and improved the child's safety and QoL

COPD: chronic obstructive pulmonary disease; NMD: neuromuscular disease; ALS: amyotrophic lateral sclerosis; TA: tele-assistance; GP: general practitioner; ED: emergency department; HMV: home mechanical ventilation; NIV: noninvasive ventilation; FVC: forced vital capacity; LTOT: long-term oxygen therapy; IQR: interquartile range; HADS: Hospital Anxiety and Depression Scale; AECOPD: acute exacerbation of COPD; QoL: quality of life; HRQoL: health-related quality of life; MD: myotonic dystrophy; S_{aO_2}: arterial oxygen saturation; IMV: invasive mechanical ventilation; OSA: obstructive sleep apnoea; AHI: apnoea–hypopnoea index; NA: not available; PAP: positive airway pressure.

value compared to regular care. Furthermore, the telemonitoring intervention used in the different studies varies, making direct comparisons difficult. Studies on cost-effectiveness of these telemonitoring interventions are limited. In a study of ALS patients that compared regular office visits in patients living close to the hospital with weekly telemonitoring *via* a modem in patients living away from the hospital, it was calculated that, although there was an economic effort required to invest in technology at the start, in-home remote monitoring of compliance to NIV resulted in a decrease in healthcare utilisation and thus eventual annual cost savings [44]. Finally, adherence to a complex monitoring protocol might drop in time. Bertini *et al.* [27] examined a protocol of once weekly nocturnal monitoring of multiple ventilator parameters *via* a multiparametric recorder, with direct access telephone counselling with the respiratory intensive care doctors when needed. They found that only 44% of patients were adherent. Patients who were more compliant with the protocol were more satisfied with the use of telemonitoring. During the study, eight patients made an urgent call to the doctor in charge of the respiratory intensive care unit, and emergency visits were avoided in five of eight cases; owing to the available information and following actions a visit to the emergency department was not necessary. Because this study was observational and uncontrolled, it is questionable whether the monitoring really prevented hospital admission or just detected abnormalities that would otherwise have remained undetected. Another specific item mentioned in the study was that patients with good compliance were over-compliant, with 114% of expected connections. This last finding raises the question of whether some patients just need reassurance, which is driven by the possibility of telemonitoring intervention [27]. Ultimately, extensive remote monitoring might load patients and healthcare professionals with extra work, and this should be weighed against the expected benefit for the patient and healthcare system. As Vitacca *et al*. [45] showed in a tele-assistance study in patients with chronic respiratory failure, there is a disparity in workload between doctor and nurse time; every new patient in the tele-assistance service required a time-consuming 73 $min \cdot month^{-1}$ for the nurse and 27 $min \cdot month^{-1}$ for the doctor. This organisational workload shift also needs to be taken into account when considering tele-assistance and telemonitoring for HMV care.

Telemonitored follow-up in patients with NMDs on HMV

Evidence for the effectiveness of telemonitoring in patients with NMD is still limited. Studies vary regarding the telehealth intervention and may be uncontrolled or nonrandomised [37]. The use of telehealth might be especially attractive for the often severely disabled neuromuscular population with rapidly progressive disease, *e.g.* patients with ALS. Pinto *et al.* [37] performed a study of weekly remote monitoring of compliance data, suggesting that this strategy reduces hospital admissions and may increase survival in ALS patients compared with a control arm. However, patients were not randomised, and the patients in the control arm had significantly worse respiratory function, limiting the conclusions of this study. In another study in 13 patients with underlying NMDs with and without HMV, symptoms and oxygen saturation were monitored daily and chest physiotherapy sessions could be prescribed according to this information. This study concluded that this approach was feasible and may lead to a reduction in emergency department admissions and hospitalisations [28]. In a 2-year follow-up period with daily monitoring, only 23 alerts were generated; it is questionable whether this small number of alerts outweighs the patient's efforts in the daily registration of signs and symptoms. Trucco *et al*. [36] described telemonitoring in ventilated adolescents with NMD in a 2-year longitudinal multicentre case-controlled trial. Arterial oxygen saturation, heart rate and ventilation parameters were uploaded weekly. If clinical conditions or parameters showed deviations, patients were contacted and necessary measures were taken. Patients on telemonitoring showed fewer hospitalisations and a shorter length of hospital stay compared to the situation prior to telemonitoring and compared to a control group.

Telemonitored follow-up in patients with COPD on HMV

In COPD patients, telemonitoring might help in detecting exacerbations and acting on them early with therapy or by adjusting ventilatory settings. Multiple studies have been performed in COPD patients without chronic respiratory failure and have shown inconsistent results due to the heterogeneity, complexity and diversity of the used telemedicine interventions [46]. In general, telemedicine interventions that provide guidance on how to act upon signals obtained (*e.g.* self-management, integrated care interventions [47], inclusion of telerehabilitation) show the most promising results [48]. In COPD patients on HMV, telemonitoring of ventilator data is attractive because daily nocturnal data on breathing can be acquired without additional patient effort. In a small pilot study performed by Borel *et al*. [49], respiratory rate and percentage of triggered breaths readouts from the ventilator software increased in the days preceding a COPD exacerbation.

There have been few important studies performed in COPD patients with chronic respiratory failure, with mixed results. Chatwin *et al*. [39] performed a randomised crossover trial of 6 months of best practice standard care alternated with 6 months with additional and quite extensive telemonitoring of symptoms and vital signs in 72 patients (39 COPD patients) with chronic respiratory disease. 87% of the patients used HMV and 63% used long-term oxygen therapy (LTOT). The primary outcome measure of time to first admission was not different between the groups, while hospital admissions and home visits were significantly increased in the telemonitoring group, self-efficacy declined, and quality of life was unaffected by the additional telemonitoring. By contrast, in a randomised controlled trial comparing tele-assistance with regular care in a mixed group of 240 patients (101 with COPD; 72% on HMV), simple monitoring with a pulse oximeter (in more severe cases with a modem system transmitting arterial oxygen saturation through a telephone line to the hospital) combined with nurse or pulmonologist consultation if needed resulted in fewer hospitalisations, fewer urgent general practitioner calls and fewer acute exacerbations in the tele-assisted group, predominantly in COPD patients [38]. In a consecutive retrospective analysis including the COPD patients of this trial, it was concluded that tele-assistance reduced the frequency of exacerbations, an effect that was even more evident in patients using nocturnal NIV.

Telemonitoring in children on HMV

In response to the problem of reduced adherence over time, Thomas *et al*. [31] described remote home monitoring of adherence, leakage and apnoea/hypopnea index over time in a cohort of 57 children (median age of 13 years) with obstructive sleep apnoea and/or nocturnal hypoventilation. Monitoring was combined with an active approach of telephone contact with the possibility of identifying problems and troubleshooting where necessary. Although 45% of questionnaire responders felt a positive contribution of monitoring in the use of the ventilator therapy, adherence was slightly lower (6.15 h) after 21 weeks compared to week 1 (6.92 h).

During the COVID pandemic, initiatives were developed to replace hospital visits by remote monitoring of patients. Onofri *et al*. [30] described a cohort of 21 children with medically complex diseases who were unable to visit the hospital during the pandemic. Children on HMV were followed by telemonitoring of the ventilator and teleconsultation. During the follow-up period, 12 healthcare problems were detected; only one problem could not be solved by a remote intervention.

An interesting development during the COVID pandemic was the use of virtual mask fitting described in a case series of three children [34]. With the help of a respiratory therapist and family caregiver, virtual measurements of the child’s face were taken, supported by members of the long-term ventilation team. An appropriate mask was then selected and evaluated for comfort and leakage by telephone or videoconference.

Ways of monitoring

Requirements and differences in various underlying diseases

There are patients with slowly progressive diseases who are dependent on HMV for many years [50], patients with rapidly progressive diseases in whom HMV is aimed at improving HRQoL and life expectancy [22, 51], and patients for whom HMV is helping them live the last period of their lives as comfortably as possible. The way patients are monitored should be aligned with their needs, possibilities, expectations and goals (table 2). Continuous monitoring of patients who remain stable for years or for whom HMV is directed at comfort only would be a burden and could be seen as an invasion of the patient’s privacy and autonomy, while infrequent *ad hoc* monitoring of patients with rapidly progressing disease with set goals would certainly miss events and might affect outcomes. In these patients, remote monitoring brings opportunities, because standard outpatient monitoring is always performed with intervals. For example, a pilot study has shown that certain parameters retrieved from the ventilator predict exacerbations in patients with COPD [49]. However, besides this study, information is lacking about what follow-up parameters predict deterioration in different diseases. Increased knowledge is needed to properly adjust monitoring frequency to the disease; the frequency should be just enough to act quickly upon deterioration while preventing too many healthcare contacts and too much stress and time spent by patients and healthcare providers reacting to events that are not related to the disease course. Therefore, remote monitoring of patients on HMV should be personalised.

Measuring more: the value of virtual care programmes/integrated care solutions

From a technical point of view, monitoring of patients at home may extend to and include multicomponent interventions based on the monitored parameters. If designed well, a virtual intervention might empower patients to become more self-efficient, as was shown in a study offering virtual assistance by a psychologist. In Ontario, Canada, a multicomponent e-health intervention has been developed (and development has been stimulated further during the COVID pandemic) for patients on home ventilatory support that enables virtual home visits, technical support, education, virtual care plans and telemonitoring of ventilators and oximeters.

TABLE 2 Important aspects of telemonitoring of home mechanical ventilation in general and with different underlying pathologies

Patients	Important aspects
All patients	Goals need to be set: what to replace? what to detect? how often? what to monitor? Discuss the workflow: action upon telemonitored signals, what is expected from the patients and what can the patient expect from the caregiver? Motivation to use the telemonitoring solution Education: sufficient technical understanding and skills to use the equipment are required Technology: - Internet access is required - Data transfer need to be secure and fulfil privacy requirements Informed consent for the transfer of data and use of remote monitoring
Slowly progressive or stable underlying conditions	Monitoring on request of the patient?
Progressive neuromuscular diseases	Continuous or frequent monitoring to detect deterioration? Limited hand function: available formal or informal caregivers needed to be educated on the telemonitoring solution
Chronic obstructive pulmonary disease	Continuous or frequent monitoring to detect exacerbations? Monitoring of additional parameters (*i.e.* symptoms) might be useful Self-management plan for early start of exacerbation treatment

The results reported in a descriptive paper state that patients connected to this "LIVE" programme felt connected, empowered and safe, and further evaluation of the programme is planned [52, 53]. However, incorporating these multicomponent interventions is challenging. The designers of the LIVE programme describe issues regarding equal access, standardisations of privacy, security and legal requirements across institutions, lack of integration in electronic health records, and limited access in patients who did not speak English or French. Furthermore, deciding on which monitored parameters to act upon and how to act upon them is a challenging question; for many diseases, it is unknown whether these parameters predict deterioration and algorithms that include several (probably connected) parameters to predict outcome are currently lacking. As long as this knowledge is lacking, designing a multicomponent analysis that results in improved outcomes as well as cost-effectiveness is challenging.

Available technology

Most ventilators are now equipped with remote access (GPRS/4G/5G) or a modem that is connected by Bluetooth technology to send data to online commercial platforms. Although a detailed discussion of available platforms falls beyond the scope of this review, in general, online platforms show summary data, *e.g.* daily ventilator use, mean or median values of tidal volume, leakage, respiratory rate, pressures achieved, inspiratory-to-expiratory time ratio and percentage of triggered breaths. It is not possible to see details, *e.g.* breath-by-breath curves, in the cloud. Connecting additional monitoring to the ventilators becomes increasingly possible (*e.g.* oximetry, transcutaneous gas exchange monitoring or polysomnography), allowing these signals to be retrieved synchronously and thereby providing us with a more detailed exploration of, for instance, PVA. However, there is one important drawback to using only commercial platforms; once you work with different ventilators, different platforms apply. Healthcare professionals therefore must log in to different systems and parameters displays vary. Attempts to connect the ventilator and monitoring equipment to a brand-independent cloud solution are therefore welcomed. Ideally, data from this cloud should be automatically transferred to electronic patient systems, so that clinical data and telemonitored data can be combined (figure 1).

Implementation of telemonitoring in HMV care

Several factors make the implementation of telemonitoring in standard care challenging. First, as explained above, remote technology to monitor HMV patients is diverse. Second, because technology is evolving rapidly, caregivers may be overwhelmed learning how to use the equipment most efficiently or how to use and interpret the increased data. At the same time, remote monitoring should be as easy as possible for patients, preferably with automatic retrieval of data without any patient effort. Therefore, it is of utmost importance that healthcare professionals, together with patients and patient organisations, define the goals they want to achieve by introducing remote monitoring and how this should then be designed. Third, telemonitoring is always subject to debate regarding the legal and privacy issues encountered when sending information *via* telemonitoring. Data might be sent using the platforms or clouds of other stakeholders (*e.g.* when using a ventilator company platform); thus, the relationship between patients and stakeholders should be governed *via* informed consent, the patient should be aware of how and where their data are retrieved and processed, and they should be informed of potential risks and confidentially issues.

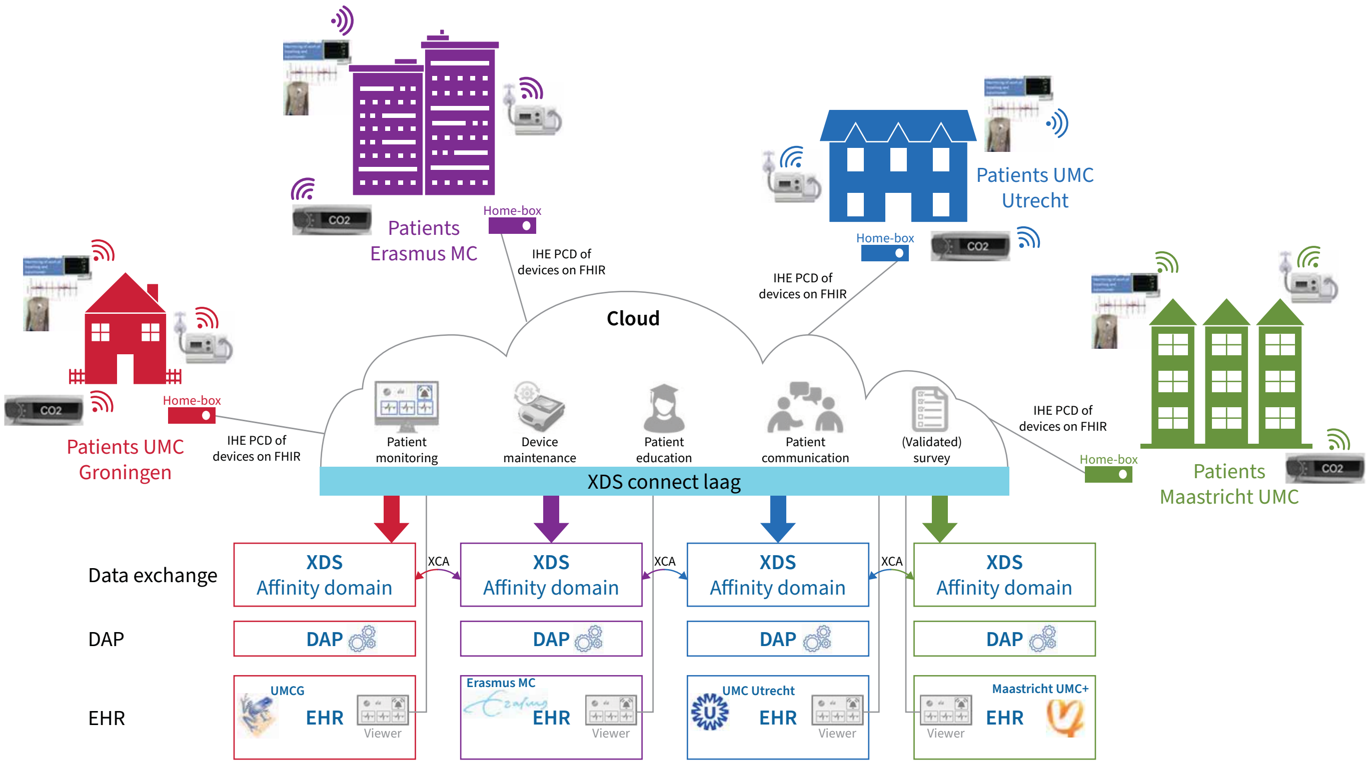

FIGURE 1 Structure in development for telemonitoring of home mechanical ventilation in the Netherlands. Various monitoring data from patients being treated by the four home mechanical ventilation centres in the Netherlands can be synchronised and collected on one platform and then sent to the different electronic patient systems and collected for research purposes. IHE PCD: Integrating the Healthcare Enterprise Patient Care Device; FHIR: Fast Healthcare Interoperability Resources (a standard describing data formats and elements and an application programming interface for exchanging electronic health records (EHRs), created by the Health Level Seven International healthcare standards organisation); XDS: cross-enterprise document sharing (facilitates the exchange of documents through registration, distribution and access across health enterprises of patient EHRs); DAP: data and analytics platform; XCA: Cross-Community Access (supports the means to query and retrieve patient-relevant medical data held by other communities).

Data transfer should be accurate, reliable (cannot be manipulated) and secure (*i.e.* data should be encoded at the highest levels to ensure that data-leakage of fragile content cannot occur). There are regulatory issues to meet, which are now uniformly covered by the European Union (EU) data protection regulation but might be different in non-EU countries. Fourth, remote monitoring does not necessarily mean that time is saved, by patients or healthcare professionals. In the studies on home initiation of NIV, the time spent by specialists to initiate one patient increased, mainly due to the increase in travel time going to the patients' home. Finally, although the economic benefit of telemonitoring use in HMV care has potential [10, 44], reimbursement of telemonitoring is in many countries not well arranged; sufficient coverage of these services lag, partly because the content of telemonitoring programmes is so diverse. Service providers could play an important role by fulfilling sub-processes of implementation.

The patients' opinion on telemonitoring in HMV care

A survey by Masefield *et al.* [54] in 2017 showed that the majority of patients and caregivers are willing to accept the benefits of monitoring their ventilator remotely (telemonitoring). However, this was an online self-reported survey and excluded those without internet access, so while these results are promising it must be borne in mind that only those who were already using the internet completed the survey. Nevertheless, studies have shown that telemedicine for HMV care is in general appreciated by patients. In a study in patients with an NMD by Ando *et al.* [55], telehealth was generally accepted and preferred to routine appointments. In an observational study by Zamith *et al.* [29] involving 9 months of telemonitoring in 51 patients with chronic respiratory failure (48% COPD), 80% of the patients felt more supported by the telemonitoring system and 75% would use it in future if available. However, 80% of the patients reported difficulty with the use the telemonitoring equipment. The study showed some potential benefits, but the conclusions are limited by the study design.

Our experience is that patients with a high level of homecare particularly expressed that the home initiation of HMV was a capital gain because their own homecare team and the general practitioner were involved from the start [11]. Patients additionally mentioned that sleeping in your own bed, adjusting at your own speed to the ventilatory support, taking part in social activities and, if applicable, being able to continue going to work were big advantages of home initiation compared to in-hospital initiation.

Questions for future research

- What parameters should be monitored remotely to ensure effective and safe home initiation of long-term HMV?
- Is telemonitoring of added value during the follow-up of HMV compared to standard hospital-based follow-up?
- Which (combination of) parameters that can be monitored remotely during HMV predict deterioration and do interventions based on these parameters improve outcomes?
- What is the ideal algorithm and organisation for remote monitoring of patients on HMV in order to improve outcomes?

Summary and future perspectives

Overall, there is an urgent need for further development and investigation of telemonitoring solutions to initiate, follow-up and adjust treatment in patients with chronic respiratory failure. It has been shown that home initiation of NIV is preferred by patients and caregivers, and that it is feasible and noninferior regarding efficiency in comparison to in-hospital initiation. Follow-up of patients on HMV could be improved and made more efficient by incorporating telemonitoring, particularly for patients living in more remote areas. However, there is a lack of evidence about which parameters need to be telemonitored and how often this should be done in different diseases to improve outcomes in a cost-effective way. Multicomponent patient-centred interventions incorporating monitoring, intervention and education seem attractive, but further investigation is needed in this field to show how this will improve care and be a feasible and cost-effective solution for the future.

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