

Editorial

The treatment burden of long-term home noninvasive ventilation

The prevalence of long-term home noninvasive ventilation (NIV) has progressively increased over recent decades, supported by evidence of clinical effectiveness in a range of conditions leading to chronic respiratory failure [1, 2]. Simultaneous technological developments have improved the reliability, portability, and comfort of devices, making NIV increasingly accessible and acceptable as a treatment option [3]. Clinicians are usually fully cognisant of the clinical outcomes they anticipate when recommending or initiating long-term NIV, for example prolonging life, preventing complications or healthcare utilisation, and/or improving symptoms. The evidence on key clinical outcomes is variable between conditions but is comprehensively evaluated in relevant clinical guidelines; traditionally less emphasis is placed on the potential practical and psychosocial implications of domiciliary NIV. However, the preferences, values and resources of individuals can have a significant impact on NIV usage and therefore may affect potential clinical benefit. This editorial discusses the healthcare-associated workload, also known as the treatment burden, of domiciliary NIV that may be shouldered by patients, their families and caregivers, justifying why the cost/benefit ratio must be carefully considered on an individual basis.

Defining treatment burden

“Treatment burden” can be described as the workload of healthcare experienced by those with chronic conditions and the impact this has on functioning and wellbeing [4]. This extends beyond side-effects and encompasses the time spent on healthcare-related activities, and the additional measures required for individuals to accept, access and use treatments. An individual’s ability to manage their healthcare workload, also known as their “capacity”, depends on numerous biopsychosocial factors including their disease burden, physical and cognitive limitations, resources, and the availability of support. They must also consider continuing to meet obligations to their personal wellbeing, and to family, the community and their professional role [5]. Individuals vary in their ability to respond to healthcare demands and, particularly in those with multimorbidity, additional treatment burden results from attempting to manage competing therapeutic needs [6]. A treatment such as NIV often leads to symptomatic benefit or the achievement of healthcare-related goals which outweigh the burden of its use [7, 8]. However, treatments with minimal perceived benefit or which exceed capacity increase the risk of negative outcomes, including poorer

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Long-term home noninvasive ventilation has practical and psychosocial implications for individuals, families and caregivers. Exploring the impact of the workload of healthcare or “treatment burden” helps determine treatment feasibility and acceptability. <https://bit.ly/39YUY2A>



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quality of life (QoL) and non-adherence [9, 10]. Largely due to intermittent contact, and focus on treatment outcomes, healthcare professionals often underestimate the required workload of healthcare and overestimate individuals' capacity to take on additional therapies, increasing the potential for them to become overwhelmed by their requirements [11].

Healthcare tasks contributing to the treatment burden of long-term home NIV

To achieve clinical benefit, domiciliary NIV needs to be used consistently and competently in the user's own environment and in the absence of direct clinical assistance. To overcome barriers to NIV use based on technological literacy, modern devices have functionalities that are intentionally simple to use and relate to. However, additional time and cognitive effort is required to develop an understanding of the correct assembly and maintenance of the NIV circuit, and to be able to recognise and arrange timely repair or replacement of equipment. In addition, most individuals have initial difficulties related to NIV tolerance, including mask leak or discomfort, ventilator asynchrony, dry throat and abdominal problems [12, 13]. Such issues are anticipated and are often discussed in advance of starting therapy. In most cases they can be adequately addressed, *e.g.* by adjusting the settings or interface, thus preventing discomfort or poor tolerance becoming reasons for sub-therapeutic use or discontinuation. At least initially, more time may have to be dedicated to trialling and adjusting the NIV circuit and to increased contact with healthcare professionals.

Most individuals for whom domiciliary NIV is indicated have complex conditions and multimorbidity [14, 15], and are therefore highly likely to have other recommended or prescribed treatments. As such, incorporating NIV into their healthcare regimen requires patients and caregivers to organise their time and balance therapeutic demands. This increases the proportion of their time dedicated to healthcare tasks, and if this becomes overwhelming, individuals may choose to prioritise those tasks with greatest perceived benefit or least required cost [11]. Use of domiciliary NIV also increases contact with healthcare systems over patients' lives due to the requirement for long-term monitoring. This typically occurs at specialist centres and therefore attendance may be inconvenient, *e.g.* due to distance, logistical issues, or the requirement to coordinate appointments with other medical needs, or professional or caring responsibilities. In addition, healthcare professionals tend to focus on their area of expertise, and if coordination with other specialists is lacking, they may have an unreasonable expectation of the individual's capacity [16].

Comorbidities may also directly or indirectly lead to practical difficulties in independent use of NIV. These include physical limitations which may be profound and related to the reason long-term NIV is required, for example in advanced neuromuscular disorders. For others, physical limitations may not be immediately apparent, for example in individuals with arthritis affecting the small hand joints, who may have difficulties with applying or removing the NIV interface. Similarly, NIV use as prescribed may be limited by cognitive problems such as dementia or learning disabilities which impact on the ability to understand the requirement for NIV, or to remember the timing or process of its use. In such cases individuals may require support from others, *e.g.* professional carers or family members, resulting in personal and potentially financial implications for both parties.

Psychosocial factors contributing to treatment burden of long-term home NIV

The initiation of long-term home NIV represents a significant lifestyle change which intrinsically requires sustained effort on the part of the patient, and often their family or caregivers. Some individuals may struggle psychologically to accept the need for domiciliary NIV, for example where this represents disease progression or deterioration [7]. Further to this, some may have difficulty with the idea of becoming "technology-dependent" and particularly in those requiring NIV 24 h a day, the fear of ventilator failure can be significant [17]. There may also be specific psychological issues such as anxiety and claustrophobia which individuals need time and in some cases specialist support to overcome. For those with end-stage disease, anticipatory planning is essential, as are discussions about the continuation or withdrawal of NIV to minimise both the burden of care and of symptoms at the end of life [18].

Individuals must adapt and plan their daily activities to incorporate using NIV on a consistent basis which for some imposes restrictions, *e.g.* on their daily routine or travel. Use of NIV during the day may limit mobility, ability to take part in social or professional interactions, or cause social embarrassment. NIV use may additionally impact on the individual's social environment and personal relationships. For example, NIV devices may cause sleep disruption for bed partners and in some cases leads to them sleeping in a separate room. This, and often the perception of the appearance of NIV and impact on body image, can lead to intimacy issues which for some are unacceptable. In addition, where individuals need support to use NIV, there may be a shift in the role and perspective of those required to help them, *e.g.* where a spouse or child

has to become a caregiver. Consideration of the impact of NIV on the caregiver in terms of QoL, education and finances are also required, and may be underestimated and overlooked [1, 19].

Depending on the country where NIV is prescribed, domiciliary use may incur direct financial costs, *e.g.* by purchasing equipment [20], which individuals may struggle to meet. It is also important to recognise that there are esoteric situations which contribute to treatment burden, particularly those related to socioeconomic disadvantage. As clinicians we have experienced some individuals who are unable to use NIV devices because they could not afford the electricity to power them, and those who have resorted to selling their device due to financial difficulties or to fund addictions. Those who have no permanent residence may also struggle to consistently use their device and further to this may have less engagement with services providing and monitoring NIV use and outcomes. Understandably, clinical outcomes are likely to be worse in those affected by such issues, due to both non-adherence to long-term NIV, and to comorbid clinical and social problems (figure 1).

Assessing and managing the treatment burden of domiciliary NIV

Evaluation of the requirements of a treatment in the context of an individual's overall healthcare workload is increasingly recognised as an important aspect of shared decision making. The overall aim of this process is to decide on the appropriateness of treatment, which not only takes into consideration anticipated clinical outcomes, but also the patient's preferences,

support, motivation and disease burden which may limit or prevent acceptance or use. These aspects are interrelated and complex, but comprehensive understanding of the individual's medical, personal and social circumstances allows clinicians to provide care that minimises disruption to their lives and maximises chances of treatment compliance. Description of treatment burden, *e.g.* frequency of NIV use, demands of device care and frequency of face-to-face review, is likely to help individuals decide if they are able to cope with the demands, and engage them in problems of adaptation to treatment [17].

Comprehensive support and coordination of care has been shown in other conditions to be important in helping manage the workload of technology-based therapies and complex treatment regimens [4, 21]. Training on technological equipment and troubleshooting is essential for all patients and caregivers, as is providing accessible and timely support as part of long-term care. In contemporary management, and particularly following changes necessitated by the COVID-19 pandemic, this may be increasingly delivered by telemonitoring and remote assessment. It is important to note that treatment burden is dynamic and is likely to change through the course of an illness [22]. For example, although many individuals struggle initially, they may find they are less fatigued and more able to cope with the practical and psychological demands of NIV when they are accustomed to using it [7]; alternatively, patients may be less able to provide self-care during periods of acute illness and need a greater level of support to continue using NIV. It is also possible that in some individuals benefit may wane over time as the underlying disease progresses or new comorbidities develop. Most trials of NIV focusing on QoL do not assess outcomes for longer than 1 year. Reevaluation of

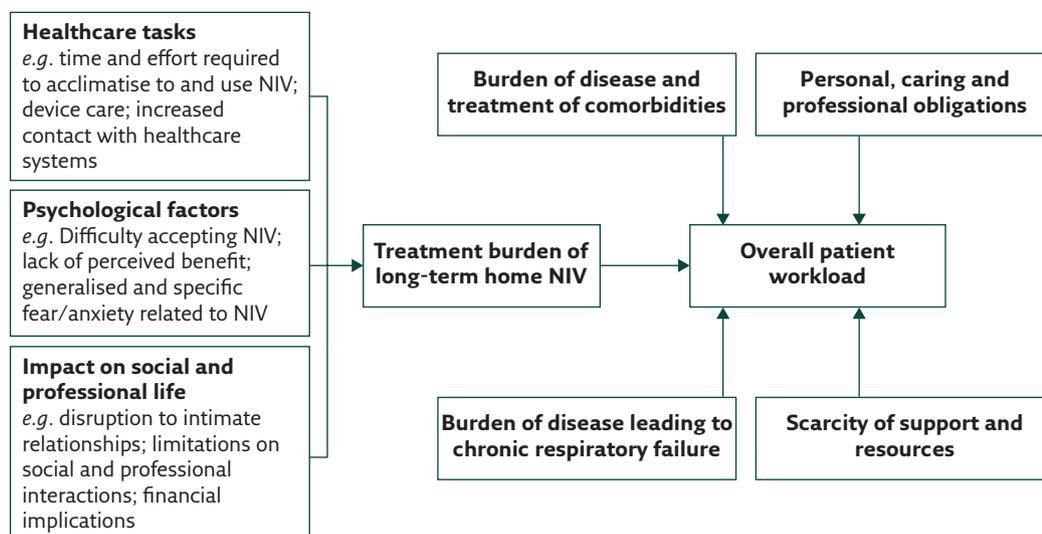


Figure 1 Summary of the treatment burden associated with NIV and other contributing factors to the overall patient workload.

positive and negative impacts should therefore be an active part of follow-up assessment.

In those presenting with poor outcomes, such as noncompliance, clinicians must consider practical and psychosocial factors that may be contributing to treatment burden, particularly where NIV comfort and tolerance have been optimised. There is a tendency for clinicians to overlook these aspects and when faced with poor outcomes, introduce more treatment steps which further overwhelm the individual's capacity, leading to feelings of failure and frustration for both patient and clinician. There is no universally accepted measure of treatment burden [23], but at least two validated questionnaires assessing treatment burden exist (the Treatment Burden Questionnaire (TBQ) [24] and the Patient Experience with Treatment and Self-management (PETS) [25]). Neither are specific for those with long-term home NIV and further investigation is required into whether these can be used alone or in conjunction with other self-assessments, *e.g.* the Severe Respiratory Insufficiency (SRI) questionnaire, a well-established specific measure of QoL in patients receiving long-term home NIV

[26], to identify domains where consistently high treatment burden is reported.

Conclusions

In providing patient-centred care and supporting long-term self-management, clinicians must provide clarity in terms of anticipated clinical outcomes, as well the practical and psychosocial demands required in using long-term home NIV. The aim of this is to help manage patient expectations, provide education regarding their condition and its treatment, and tailor management to enable it to be feasible and acceptable on a long-term basis. In situations where NIV leads to or risks overwhelming an individual's capacity, particularly in conditions where there is limited or equivocal evidence supporting the long-term use of NIV, consideration must be made as to whether the treatment burden outweighs the potential treatment benefit. This may allow the resources of the individual and the healthcare provider to be used more constructively and improve satisfaction and outcomes for both.

Key points

- Treatment burden is the workload of healthcare and its impact on the individual's functioning and wellbeing.
- Long-term home NIV requires sustained physical and psychosocial effort on the part of the patient and their family and caregivers.
- Overburden of treatment may lead to adverse outcomes such as noncompliance and force individuals to make decisions about treatment prioritisation.
- Shared decision-making should involve providing education and outlining potential treatment burden before starting long-term home NIV.
- Particularly in cases of poor compliance, the need to introduce further treatment may be avoided by identifying and addressing aspects contributing to current treatment burden.

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Conflict of interest

None declared.

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