



Title	Invasive Home Mechanical Ventilation, Mainly Focused on Neuromuscular Disorders
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Aim

To assess medical, social, economic, and ethical aspects of invasive home mechanical ventilation for patients with chronic respiratory insufficiency due to neuromuscular diseases.

Conclusions and results

Analysis of the literature shows that invasive mechanical ventilation may improve symptoms of hypoventilation. An increase in life expectancy is likely, but for ethical reasons it is not confirmed by premium-quality studies. Complications (eg, pneumonia) are rare. A study regarding the pneumonia ratio reports 1.89 pneumoniae/1000 ventilator days in the first 500 days of invasive ventilation. This is a frequent reason for rehospitalization of patients, but the prognosis is favorable. Mobile home ventilators differ regrettably in their technical performance. Some studies compare the economic aspects of in-hospital ventilation to outpatient ventilation. The included studies report a 62% to 74% reduction for in-home care via an ambulatory nursing service, in comparison to the costs that accumulate in the intensive care unit of a hospital. Higher expenses arise due to the necessary equipment and the high cost of time for highly qualified staff in the partial 24-hour care of affected patients. However, none of the studies applies to the German provisionary conditions. The results of quality-of-life studies are mostly qualitative. Caregivers of ventilated patients report positive as well as negative ratings. From a legal standpoint the code of social law (*Sozialgesetzbuch V*) regulates the financing of home ventilation, especially invasive mechanical ventilation, requiring specialized technical nursing. The absorption of costs is distributed among different insurance carriers. Hence, the necessity to enforce a claim of cost absorption often arises in exercising the basic right of free choice of location.

Recommendations

For a so-called “participative decision” – made by the patient after intense counseling – early and honest patient education on the pros and cons of invasive mechanical ventilation is needed. Not only long-term survival, but also quality of life and individual, social, and religious aspects must be considered.

Methods

Fixed criteria were used to view and select literature found through a systematic literature search of 31 relevant databases in 2008. The analysis included randomized controlled studies, systematic reviews, health technology assessment (HTA) reports, clinical studies of >10 patients, health economic evaluations, primary studies with particular cost analyses, and quality-of-life studies related to the research questions. See Executive Summary link at http://portal.dimdi.de/de/hta/hta_berichte/hta268_summary_en.pdf.

Further research/reviews required

The literature does not address differences in quality of life associated with the type of outpatient care. A registry of home ventilation and research to ascertain valid data are necessary to improve outpatient structures. Specific German data is needed in the future to adequately depict the national concepts of provision and reimbursement.