

Prolonged Mechanical Ventilation in Massachusetts: The 2006 Prevalence Survey

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BACKGROUND: Prolonged mechanical ventilation and home ventilation impose unique challenges on patients, families, and the healthcare system. In the absence of a centralized database to track prolonged and home ventilation, there has been a paucity of prevalence studies, and what is known is outdated. We surveyed respiratory care managers working in the state of Massachusetts to estimate the prevalence and locations of prolonged and home ventilation in 2006. **METHODS:** We invited 113 respiratory care managers practicing in acute-care hospitals, long-term acute-care facilities (also known as weaning units, step-down units, and long-term-ventilation units), and home-care companies to participate in a Web-based survey. We matched the responses to their respective institutions and analyzed the results according to hospital size, location (urban or suburban), and whether the institution was a teaching institution. **RESULTS:** In December of 2006 there were 817 ventilated patients, of whom 460 met the criteria for prolonged ventilation (> 21 d for at least 6 h/d) and 221 met the criteria for home ventilation (ventilation for any period of time at home). Of the 239 patients not at home, 64 were in acute-care hospitals, 175 in long-term acute-care facilities, and 221 at home. The survey response rate was 86% for acute-care hospitals with \geq 400 beds, 48% for acute-care hospitals with < 400 beds, 65% for long-term acute-care facilities, and 67% for home-care companies. The non-respondents were primarily smaller, suburban, non-teaching hospitals, which have a low prevalence of prolonged-ventilation patients. Among the home-ventilation patients, the majority had neuromuscular diseases, were < 65 years old, and were ventilated via tracheostomy tube. The most important limitations to transitioning prolonged-ventilation patients to home ventilation appeared to be lack of family and/or economic support. **CONCLUSIONS:** In Massachusetts, the estimated prevalence of prolonged and home ventilation increased from 2.8/100,000 inhabitants in 1983 to 7.1/100,000 inhabitants in 2006, and the majority of them are in long-term acute-care facilities, large urban teaching hospitals, and at home. *Key words:* artificial respiration; prolonged mechanical ventilation; home ventilation; survey; prevalence; neuromuscular diseases; COPD; obstructive sleep apnea; health care surveys; ventilators. [Respir Care 2010;55(12):1693–1698. © 2010 Daedalus Enterprises]

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Introduction

The systematic application of mechanical ventilation following the polio epidemic of the 1950s led to dramatic improvement in survival from acute respiratory failure. However, up to 20% of critically ill patients may require prolonged mechanical ventilation, which imposes unique challenges to patients, families, and the healthcare system.^{1,2} It is important to determine the prevalence and location of prolonged-ventilation patients, including those on home ventilation, because their care implies a level of medical severity and fragility associated with specialized support and utilization of substantial resources.

In the United States there is no national database to track ventilator-dependent patients. However, it is believed that the number of patients requiring prolonged ventilation is increasing.³ There is a paucity of published prevalence studies on prolonged ventilation, and what is known is outdated.⁴⁻¹⁰ The best study of the prevalence of prolonged ventilation in the United States was a 1991 survey by the American Association for Respiratory Care (AARC) and Gallup, which randomly surveyed 300 directors of respiratory care and 100 pulmonologist across the United States, and extrapolated a prevalence of 11,419 patients or 4.6/100,000 inhabitants. They also found that these patients were mostly concentrated in larger (> 400 beds) urban hospitals.¹⁰

At a state level, Make et al⁹ estimated in 1983 a prevalence of 2.8/100,000 inhabitants in Massachusetts, and more than 90% were in intensive care units (ICUs). A decade later, Harris et al⁸ reported a similar prevalence but found that a larger number of patients were in long-term acute-care facilities, also known as weaning units, step-down units, and long-term-ventilation units. In 2005, Graham et al¹¹ conducted a survey in Massachusetts to determine the prevalence of daily use of noninvasive, negative-pressure, and invasive/transtracheal ventilation in pediatric patients up to 22 years of age. They counted 197 prolonged-ventilation children (3.1/100,000 inhabitants), and 70% of them were at home, which is a nearly 3-fold increase over a 15-year interval. The prevalence information for adults has not been updated, and the number has probably increased as a result of improved ICU survival¹² and an increased number of patients with chronic diseases that require mechanical ventilation.^{5,6,13,14} On the other hand, the locations of those patients may have changed because of the proliferation of weaning/long-term-ventilation units, and the impact of managed care.

The primary aim of this study was to update our understanding of the prevalence and distribution of prolonged-ventilation patients, including patients on home ventilation, in Massachusetts, December 2006 to February 2007. The secondary aim was to explore the possible limitations to home discharge of these patients.

Methods

This research was performed at Brigham and Women's Hospital, Boston Massachusetts; Kindred Hospital Boston, Boston Massachusetts; and Caritas St Elizabeth's Medical Center, Brighton Massachusetts. Our institutional review board approved the study.

Definitions

We used the currently accepted case definition for prolonged mechanical ventilation, which is ventilation for 21 consecutive days for at least 6 h/d.¹⁵ We defined home ventilation as mechanical ventilation employed in the user's home, regardless of hours of daily use, but not including patients using home ventilation only for sleep-disordered breathing, whom we excluded.

Survey

Our strategy to identify prolonged-ventilation and home-ventilation patients assumed 2 premises: first, that the patients who are not at home are in facilities that provide respiratory care services, and, second, that for a patient to use mechanical ventilation at home a ventilator has to be either rented or purchased and must have a service agreement through a home medical equipment provider. Therefore, our survey targeted managers in such facilities. We used the Massachusetts Society for Respiratory Care database, and the New England Medical Equipment Dealers Association database, which lists home-care companies that provide ventilator equipment.

We created a survey and administered it with a Web-based survey tool (<http://www.SurveyMonkey.com>, Portland, Oregon). The survey had 7 single-choice or multiple-choice factual questions, and 1 open-ended opinion question. We assessed the survey's clarity and completeness in pilot tests with 8 respiratory therapists and 3 critical care physicians.

First we sent a pre-notification communication to all recipients, stating the nature and aims of the study and the investigators' affiliation and endorsement (survey salience). The invitation to participate in the survey was distributed in December 2006, via an e-mail sent by the president of the Massachusetts Respiratory Care Society, to 113 respiratory care department managers. The e-mail contained a hyperlink to the survey. The managers' telephone and postal addresses were not shared with the research team. We sent 2 reminders, 2 weeks apart, to those who did not respond to the survey. The survey was closed in February of 2007.

We matched each survey respondent to his or her hospital/institution. The survey software prevented multiple responses (ie, allowed only one response per recipient),

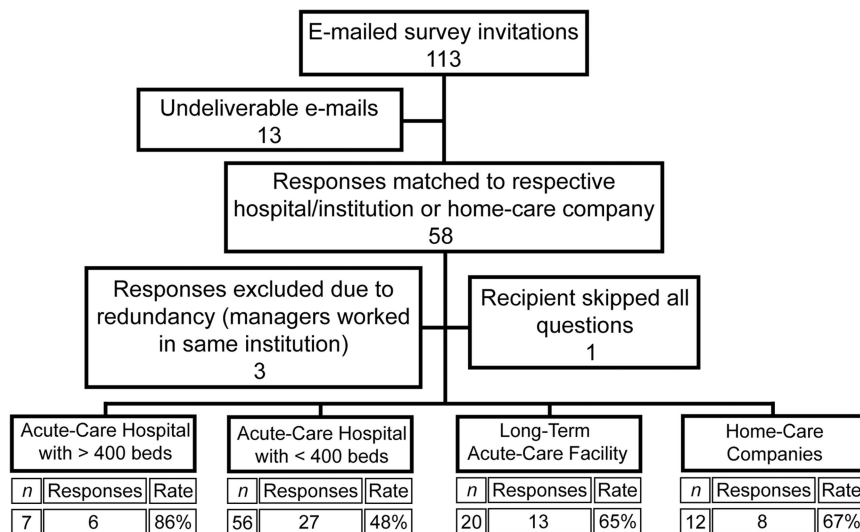


Fig. 1. Survey invitations, responses, exclusions, and respondent categorization.

and we identified responses from different managers who worked in the same institution, to prevent duplicates.

For the home-ventilation patients we requested demographic data, including age range (< 18 y, 18–65 y, or > 65 y); disease category; type of patient interface (tracheostomy, nasal mask, face mask, or mouthpiece); and type of ventilation (invasive, noninvasive, positive-pressure, or negative-pressure). We excluded patients who used mechanical ventilation only for sleep-disordered breathing.

Data Analysis

We collected the data cumulatively, but we reviewed individual responses for internal consistency and to avoid data duplication. We collected the data in a spreadsheet (Excel 2003, Microsoft, Redmond, Washington) and conducted the analysis with statistics software (InStat 3.01, GraphPad Software, San Diego, California). We summarized binary and categorical variables with frequency counts and percentages. We present normally distributed continuous variables as mean ± SD. We used the independent *t* test to compare groups. We compared categorical variables with Fisher’s exact test. A *P* value < .05 was deemed significant.

We categorized the patients’ locations by the respondents’ institutions, per the terms used by the Massachusetts Hospital Association (<http://www.mhalink.org/public/mahospitals>) and the National Association of Long-Term Hospitals (<http://www.nalth.org>): acute-care hospital; long-term acute-care facility (ie, all non-ICU clinical sites that care for mechanically ventilated patients, also known as long-term hospitals, weaning units, step-down units, and long-term-ventilation units); and home-care company.

We also categorized the institutions by number of beds (≥ 400 beds or < 400 beds), location (urban or suburban, based on data in the national atlas, <http://www.nationalatlas.gov/natlas/natlasstart.asp>), and whether the institution was an academic/teaching facility (<http://www.mhalink.org/public/mahospitals>) as suggested by the AARC/Gal-lup¹⁰ and Eurovent studies.¹⁶

Results

We e-mailed survey invitations to 113 respiratory care managers. Thirteen of the e-mail addresses did not reach the recipients. There were 58 respondents (Fig. 1). According to the Massachusetts Hospital Association (<http://www.mhalink.org>), in 2006 Massachusetts had 7 acute-care hospitals with ≥ 400 beds (mean ± SD 576 ± 132 beds), and 56 acute-care hospitals with < 400 beds (167 ± 103 beds). There were 20 long-term acute-care facilities (125 ± 142 beds). There were 12 home-care companies that provided home mechanical ventilation services. We excluded 3 responses as duplicates, from different managers in the same institution. All 7 factual questions were answered by all except for one respondent, who did not answer any of the questions. Thirty-one respondents answered the opinion question about potential limitations to home discharge.

Figure 2 shows the patient locations. There were 817 ventilated patients in Massachusetts during the study period, of whom 239 met criteria for prolonged mechanical ventilation and 221 for home mechanical ventilation. Of the 239 patients not at home, 73% were in the 13 long-term acute-care facilities that responded (11 ± 8 patients per long-term acute-care facility); 19% in the 6 hospitals with ≥ 400 beds that re-

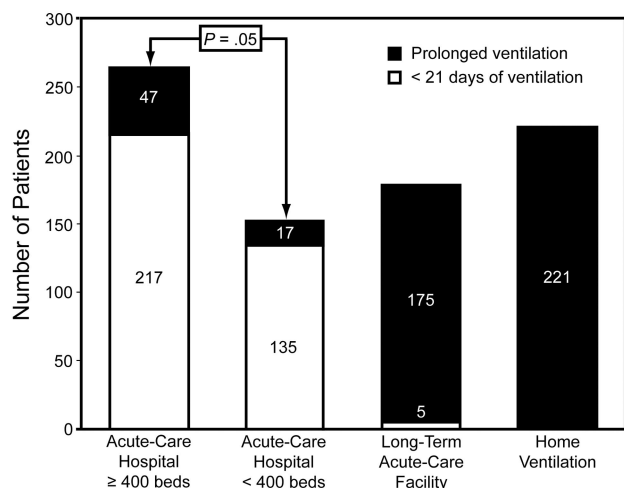


Fig. 2. Distribution of mechanically ventilated patients, stratified by duration of ventilation (prolonged ventilation means ≥ 21 days) and patient location.

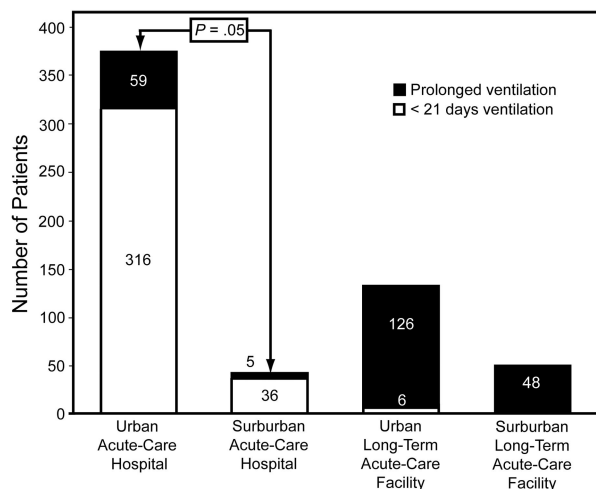


Fig. 3. Distribution of mechanically ventilated patients stratified by duration of ventilation (prolonged ventilation means ≥ 21 days) and facility location and type.

sponded (8 ± 7 patients/hospital); and 7% in the 23 hospitals with < 400 beds that responded (1 ± 2 patients/hospital). The response-rate difference between the large and small hospitals was statistically significant.

Fifty-nine prolonged-ventilation patients were in the urban acute-care hospitals, 5 were in the suburban acute-care hospitals, 126 were in the urban long-term acute-care facilities, and 48 were in the suburban long-term acute-care facilities (Fig. 3). Fifty-five prolonged-ventilation patients were in the teaching hospitals (5 ± 7 patients per teaching hospital), and 9 were in the non-teaching, community hospitals (0.4 ± 1 patient per non-teaching hospital). Table 1 describes the 221 home-ventilation patients.

Table 1. Characteristics of the 221 Patients on Home Mechanical Ventilation

	No. (%)
Disease Category	
Neuromuscular disease	152 (69)
COPD or other obstructive lung disease	51 (23)
Other: chest wall or thoracic	18 (8)
Age Range (y)	
< 18	92 (41)
18–65	114 (52)
> 65	15 (7)
Interface	
Tracheostomy tube	172 (78)
Nasal mask	29 (13)
Face mask	18 (8)
Mouthpiece	2 (1)
Usage (h/d)*	
< 6	39 (44)
6–12	5 (5.5)
13–18	40 (46)
24	5 (5.5)

* Data available for only 89 patients.

In the respondents' opinions, the 3 most common reasons that prolonged-ventilation patients could not be sent home were: lack of family support (61%), lack of reimbursement by insurers for home nursing personnel (35%), and economic limitations (32%).

To estimate the impact of non-response bias, we compared the respondents and non-respondents (Table 2). Eighty-one percent of the non-respondents worked in smaller non-teaching suburban acute-care hospitals. For the long-term acute-care facility sector, the respondents and non-respondents were similar in institution size and location. Thus, the low response rate of the acute-care hospitals may have little impact on the prevalence estimation, as we calculate that there were approximately 15 missing patients in the acute-care hospitals if we extrapolate the mean number of prolonged-ventilation patients multiplied by the number of non-responses in this category. Based on the same assumption, we estimate 84 missed prolonged-ventilation patients in the long-term acute-care facilities.

Based on the projected 2006 Massachusetts census population of 6,437,193 residents,¹⁷ our conservative estimated prevalence of prolonged-ventilation patients (including those on home ventilation) is 7.1–8.3/100,000 inhabitants (95% CI 7.0 to –7.2), and for the home-ventilation subgroup 3.4/100,000 inhabitants (95% CI 3.3 to –3.5).

Discussion

The present study provides an updated estimated prevalence for prolonged-ventilation patients in Massachusetts

Table 2. Facilities Surveyed

	Respondents	Non-respondents	P
Acute-Care Hospitals			
Beds (mean ± SD)	280 ± 174	138 ± 121	< .001
≥ 400 beds (n)	6	1	NA
Beds (mean ± SD)	568 ± 132	630	NA
< 400 beds (n)	27	29	NA
Beds (mean ± SD)	216 ± 103	121 ± 79	< .001
Urban (%)	61	30	.02
Teaching (%)	30	10	.04
Long-Term Acute-Care Facilities*			
Beds (mean ± SD)	121 ± 177	139 ± 68	.80
Urban (%)	77	43	.14

NA = not applicable

*This category includes weaning units, step-down units, and long-term ventilation units.

in 2006: 7.1–8.3/100,000 inhabitants, and 3.4/100,000 inhabitants for the home-ventilation subgroup. Prolonged-ventilation patients were more likely to be in long-term acute-care facilities (a trend already observed by Harris et al⁸ in 1997) and to be in large urban teaching institutions (a finding consistent with the 1991 AARC/Gallup survey).¹⁰

Our results suggest a 2.6-fold prevalence increase in prolonged-ventilation patients in Massachusetts, compared to the 1986 report by Make et al.⁹ Our results agree with those of Graham et al,¹¹ who found an absolute number of 197 ventilator users in the Massachusetts pediatric population surveyed in 2005. That represented a 3-fold increase in prevalence of the pediatric prolonged-ventilation population over 15 years. The increase was not limited to patients in the acute-care and long-term acute-care sectors, but extends to the home-care sector. The number of Massachusetts Health home-ventilation patients was corroborated by a Massachusetts Health official (personal communication, 2010, Lynda Scully, Manager for Durable Medical Equipment, Office of Long-Term Care, MassHealth).

Life at home is the ultimate goal of most prolonged-ventilation patients. The present survey shows an increase in the number of home-ventilation patients, compared to previous reports.⁹ There are several reasons why more prolonged-ventilation patients appear to be reaching home. First, it may reflect the particularly high density of university hospitals in Massachusetts and the longevity (over 20 years) of the home-ventilation programs in this state. Both of these factors were described as being independent predictors of higher numbers of home-ventilation users in the 2001 Eurovent European home-ventilation survey.¹⁶ Second, the home-ventilation option, which is indicated for younger neuromuscular patients, creates a cohort of individuals who are more likely to be on mechanical ventilation for more than 6 years,¹⁶ possibly adding to the

cumulative prevalence of prolonged ventilation. Interestingly, our survey suggests that the preferred interface for home ventilation is tracheostomy (76%), despite the fact that half the patients require ventilation for less than 13 hours a day. We speculate that they may be a less respiratory-compromised population who are therefore able to go home, and tracheostomy may be the most reliable and safe ventilator-patient interface, especially in the pediatric population. Despite the increase of the number of home-ventilation patients, the goal of sending ventilated patients home remains elusive in the majority of patients who have difficulty weaning from mechanical ventilation. It seems that the ultimate determinants of successful home discharge continue to be availability of family support and reimbursement for services (including nursing) by insurers. Little has changed, because the same reasons limited the possibility of sending prolonged-ventilation patients home more than a decade ago.^{18,19}

Limitations

Data obtained via a self-administered survey depend on respondent motivation, honesty, recall memory, and ability to respond. Despite several strategies to optimize survey response, our overall response rate of 54% probably led to an underestimate of the prevalence of prolonged ventilation and home ventilation. Interestingly, the response rate was lowest among the respiratory care managers in the smaller (< 400 beds) hospitals. This is important because most prolonged-ventilation patients cared for in ICUs tend to be concentrated in large (> 400 beds) urban centers (an observation reported in 1991 by the AARC/Gallup United States survey).¹⁰ The next lowest response rate was from the long-term acute-care facilities sector, where the small sampling universe (20 units) undoubtedly leads to underestimation of the actual number of prolonged-ventilation patients. In the absence of a centralized ventilator

database registry, surveying the respiratory care managers continues to be the most reliable alternative. Survey has been the predominant method in the majority of studies of prolonged-ventilation prevalence.^{7-11,16,20,21}

For the targeted survey population, where e-mail is part of their corporate communications, the use of a Web-based survey method probably does not affect the response rate or answers. This was confirmed in previous studies that compared e-mail surveys to paper mailed surveys.²²⁻²⁵ Updated data with an estimated low impact from non-response bias is better than outdated or presumptive calculations based on estimated projections.³

Since our survey did not include individual patient demographic data, duplication may have occurred. However, the survey software prevented duplicate answers from a given respondent, and we excluded responses from different managers working in the same institution. Another consideration created by the lack of individual demographic data is the omission of patients who reside in Massachusetts but receive their care from a hospital or home-care company in a neighboring state, and inclusion of patients who reside in a neighboring state but receive care in Massachusetts. We believe that the impact of this effect is minimal, but its true dimension needs to be studied.

Conclusions

Our survey results suggest that the number of prolonged-ventilation patients in Massachusetts has increased and may have doubled over the last 10 years. Long-term acute-care facilities have decongested ICUs and possibly offered a better setting to train families to be caregivers to home-ventilation patients. Given these patients' resource-intensive requirements, it may be justifiable to develop a centralized registry that monitors incidence, prevalence, and demographic data to assist in the planning, resource-allocation forecasting, and recycling of equipment, as has been the practice for decades in Europe.^{18,26}

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