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# OUTCOME OF HOME MECHANICAL VENTILATION

Nawal Salahuddin, Khurshed Haider, Shahid Javed Husain, Ali Bin Sarwar Zubairi, Shahla Siddiqui,\* Fazal Hameed\* and Roshan Manasia\*\*

## ABSTRACT

**Objective:** To determine the outcome of patients discharged home on portable ventilator.

**Design:** Descriptive study.

**Place and Duration of Study:** The Aga Khan University Hospital, Karachi from January 2000 to December 2004.

**Patients and Methods:** All ventilator-dependent patients discharged home were contacted. Survivors were administered the EQ-5D Quality-of-Life instrument. SPSS version 13 was used to analyze data.

**Results:** Eleven patients were discharged home on invasive ventilation. Mean age was 49 years (range 10-98 years). Cause of ventilatory failure were cervical spine trauma in 36%, primary neurological disease in 27%, critical illness neuropathy and respiratory failure in 18% each. Survival rate was 73%, with three deaths. Mean duration of ventilation was 9.45 months (95% CI 3.24, 15.67). Rate of successful weaning after discharge was 36%, with 4 patients off all forms of ventilatory support and 2 on only nocturnal support. A 2.8 (95% CI 0.5, 16.6) relative risk towards successful weaning was associated with the presence of a family member as the primary care giver. Mean scores on the EQ-5D descriptive tool were; mobility 2 ( $\pm 0.82$ ), self-care 2 ( $\pm 0.82$ ), usual activities 1.86 ( $\pm 0.69$ ), pain/discomfort 1.43 ( $\pm 0.79$ ), anxiety/depression 1.29 ( $\pm 0.76$ ). Mean score on the EQ-VAS was 48.2 ( $\pm 27.3$ ).

**Conclusion:** In carefully selected patients, home ventilation is a viable option with the expectation of successful weaning and survival. Patients discharged home on ventilation reported a reasonably good quality of life with proportionately more problems related to independence compared to overall well-being.

**KEY WORDS:** Home ventilation. Critical care. Rehabilitation. Respiratory failure.

## INTRODUCTION

Technological advances and widespread availability of critical care services in Pakistan has led to increasing number of patients surviving the initial illness. A small number may become clinically stable but require ongoing assisted ventilation. They occupy scarce ICU beds and accrue huge monetary and emotional costs related to prolonged hospitalization. Moreover, the ICU fosters dependence and limits rehabilitative efforts.

Chronic ventilation, either at home or facility-based, has become accepted practice for such patients.<sup>1</sup> Unfortunately, at present, there are no such facilities or home health services available in Pakistan. The World Health Organization recently ranked Pakistan 122 in 'overall health systems performance'.<sup>2</sup> Appropriate resource allocation has thus become imperative needs.<sup>3</sup> A reasonable option would be to develop home-based ventilation with the close involvement of families and friends of ventilator-dependent patients as care providers.<sup>4</sup>

At the Aga Khan University Hospital, carefully selected patients have been discharged on home ventilation. The families are assisted in arrangements for 24-hour nursing, portable ventilator, domiciliary oxygen, and respiratory care

equipment prior to discharge. Private nurses are trained by the ICU staff. Patients are then sent home once the patients, their families and critical care staff is assured of the safety for home discharge.

In this report, we describe the outcomes of our patients sent home on invasive mechanical ventilation.

## PATIENTS AND METHODS

A descriptive study was carried out at the Aga Khan University Hospital from January 2000 to December 2004. All patients who were discharged home on invasive ventilation were included. The outcome variables were weaning, survival and health-related Quality-of-Life. Quality-of-Life was measured using the EuroQOL (EQ-5D). This is a standardized, validated, generic measure of health states. It provides a simple 5 domain (mobility, self care, usual activities, pain/discomfort, anxiety/depression) descriptive profile and a single index value (score on visual analogue scale).<sup>5-7</sup> We used an Urdu translation obtained from the EuroQOL group. Clinical data was obtained by reviewing medical records. Patients or their families were visited at home. Out-of-Karachi residents were contacted by telephone and the primary caregiver was used as intermediary to administer the questionnaire directly to the patient.

Data was analyzed using the Statistical Program for Social Sciences (SPSS) version 13. Descriptive variables were reported as mean or median  $\pm$  SEM. Relative risk was calculated using a standard 2x2 table.

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## RESULTS

Eleven patients included 8 females and 3 males. Mean age was 49 years (range 10 - 98 years). Causes of ventilatory failure were high-cervical spine trauma in 36%, primary neurological disease (motor neuron disease, craniovertebral anomaly, mitochondrial myopathy) in 27%, critical illness neuropathy in 18% and respiratory failure (COPD, obesity-hypoventilation syndrome) in 18%.

Ten patients were discharged on portable ventilators; LP-6 or LP-10. One patient went home on a BiPAP (Respironics, PA) machine. Ventilator settings were A/C or SIMV modes, tidal volumes set to 8 ml/kg and respiratory rates adjusted to maintain adequate gas exchange. For the BiPAP device, inspiratory and expiratory pressures were titrated to achieve optimal gas exchange as measured by arterial blood gases (ABGs). Six patients received a ventilator donated by a charitable trust, 3 patients rented and two patients directly purchased a machine; LP-6 ventilator and BiPAP device. The average costs incurred were between Rs. 250,000 - 300,000.

Overall survival rate was 72% (n = 8). Of the 3 patients who died; one was a 98 years old female with COPD with 3 months survival after discharge. Another was a 63 years old female with cervical spine trauma who also had renal failure and died of sepsis at 6 months, and the third was a 48 years old male with bilateral diaphragmatic weakness and coexisting congestive heart failure and diabetes. He died of an acute MI 12 months after discharge.

Mean duration of ventilation was 9.45 months (95%CI 3.24, 15.67). Rate of successful weaning after discharge was 36%, with 4 patients off all forms of ventilatory support by 6 months of hospital discharge. Two patients (25%) were dependent only on nocturnal ventilatory support and 2 (25%) continued to be completely ventilator dependent. A 2.8 (95% CI 0.5,16.6) relative risk ratio towards successful weaning (complete and partial) was associated with the presence of a family member as the primary care giver compared to a private nurse alone. Patient numbers 1, 3, 4, 5, 6, 10 and 11 had first-degree family members (husband, father, sister) who took responsibility of ventilator management whilst the patient was still in the ICU. Survivors scored a mean score of 48.2(± 27.3) on the EQ-Visual analogue scale mean scores on the individual domains of the EQ-5D descriptive tool were; mobility 2 (± 0.82), self-care 2 (± 0.82), usual activities 1.86 (± 0.69), pain/discomfort 1.43(± 0.79), anxiety /depression 1.29 (± 0.76) (Figures 1 and 2).

## DISCUSSION

Prolonged mechanical ventilation has become usual practice in the care of chronic ventilatory failure. In developing countries, such as Pakistan, the development of chronic ventilation facilities would be a drain on already scarce resources. Home ventilation is an option, since such individuals can be maintained at lesser costs in the community than the hospital.<sup>8</sup>

Our result of a 73% survival is similar to those reported in the literature. Chu *et al.*<sup>9</sup> reported the results of a retrospective survey of 249 patients on home ventilation in Hong Kong. The overall survival was 66.3%. Douglas *et al.*<sup>10</sup> reported a 1-year mortality rate of 64.7% in 538 patients discharged on home

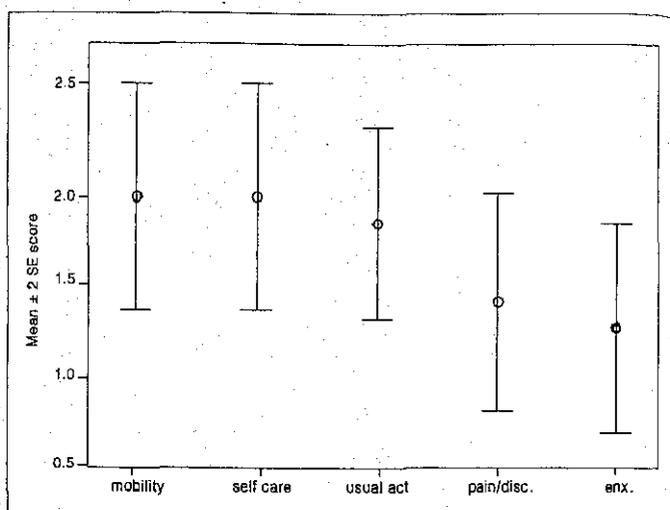


Figure 1: Graphic representation of mean (± SEM) score on descriptive domains of EQ-5D quality-of-life instrument.

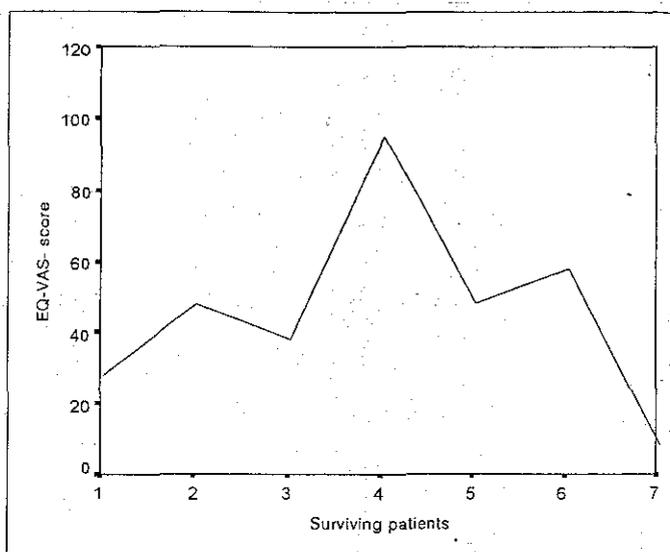


Figure 2: Graphic depiction of scores on EQ-VAS for patients on home ventilation.

ventilation.<sup>10</sup> Winterholler<sup>11</sup> described the outcomes of 31 with progressive neuromuscular diseases. The mean observed ventilation time was 565 days with a mean survival of 82 to 2052 days in the various severity groups.

Survival on home ventilation has been related to a number of factors. The ANTADIR (Association Nationale pour le Traitement a Domicile de l'Insuffisance Respiratoire Chronique) observatory study described 21,957 patients on home ventilation through a tracheostomy.<sup>12</sup> They reported an association between etiology of respiratory failure and survival, with the best outcomes in patients with kyphoscoliosis (8 years), followed by neuromuscular diseases (6.5 years) and COPD (3 years). Chelluri's group<sup>13</sup> reported advanced age, comorbidity and pre-hospital functional status as predictors of mortality in 817 patients receiving prolonged ventilation.

Our patient groups comprised 5 patients (45.4%) with primary neuromuscular diseases leading to ventilator dependence. The 3 deaths we observed, all occurred in patients with advanced age (98 years) or those with active comorbid conditions.

Weaning from ventilation has conventionally been carried out at chronic weaning facilities where rehabilitation is the focus.<sup>13</sup>

The rates of successful weaning reported from such centers are from 22%<sup>14</sup> to 32.7%.<sup>15</sup> We observed a successful wean rate of 36%, with a strong (relative risk 2.8, 95% CI) association between weaning (complete or partial) and family members as primary caregivers compared to a private nurse. We found it remarkable that successful weaning with survival was carried out by the family and consider it our most important finding. An evaluation of outcomes of home ventilation should incorporate the patient's perspective of the outcome. Discharge to home is meaningless without an assessment of health-related Quality-of-Life (HRQOL). HRQOL is generally measured by taking into account the physical, psychological and social domains of health.<sup>16</sup> We used a generic instrument, the EQ-5D, which has been validated in postcritical care patients, patients with neuromuscular disease<sup>17-21</sup> and in patients of differing ethnicities.<sup>20-26</sup> The EQ-5D has also been shown to be reliable when reported by proxy, i.e. care givers.<sup>27</sup> Patients discharged on home mechanical ventilation (HMV) generally report a good HRQOL. Goldstein *et al.* reported the results of a health satisfaction survey in 98 patients on HMV; 87% reported an overwhelmingly positive impact on their lives.<sup>8</sup> Forty-three percent of their patients had neuromuscular weakness leading to respiratory failure. Markstrom and colleagues reported good perceived health, despite physical limitations in 91 patients with skeletal and neuromuscular diseases on HMV.<sup>29</sup> In our study, patients reported scores consistent with moderate-to-severe difficulty in independent living activities but scored mild problems with pain perception and anxiety, depression with a mid-score (mean VAS 49) on the overall perceived HRQOL. Home mechanical ventilation is an unorthodox treatment modality for Pakistan, since most physicians are reluctant to discharge ventilator-dependent patients under the care of their families alone. Other than a single case report from India<sup>30</sup>, there is no other data from this region.

## CONCLUSION

In carefully selected patients, home ventilation is a viable option with the expectation of successful weaning and survival. Patients discharged home on ventilation reported a reasonably good quality of life with proportionately more problems related to independence compared to overall well-being.

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