Understanding the Outcomes That Matter to Patients and what influences these : An International Survey of Patients Treated by Home Mechanical Ventilation (HMV).



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AIMS

For patients with respiratory failure, Home Mechanical Ventilation (HMV) is today a standard care of treatment, however little focus has been given to understanding the outcomes that matter to patients who receive this treatment.

One of the challenges in looking at this area is that respiratory failure affects people across different disease types, the most common being Chronic Obstructive Pulmonary Disease (COPD), Neuromuscular Diseases (NMD) and Obesity Hypoventilation Syndrome (OHS).

We therefore took the approach to understand the outcomes of the patients receiving HMV and how the underlying disease and other factors influence these. In doing this we were also looking to understand how these factors could influence HMV service provision and how we can segment and profile our patients to ensure best quality of life. This was a key goal in the project as patients today are managed by homecare providers in a very generic way with the focus being on the device and not on interventions that are not based on the needs of the patients or their carers.

METHODS

The starting point for this project was to ask patients what matters to them. This was done through a 12 question survey which was deployed in 12 countries (Europe, Asia and Americas) to HMV patients aged 18 years or over. Information about patients' pathology, sociodemographic characteristics, and therapy were collected and patients were asked to select the 5 outcomes most important to them from a list of 14.

The list of 14 outcomes selected for the questionnaire came from literature searches to understand what work had already been done in this field. This included reviewing the ICHOM standards which may correlate to patients receiving HMV. Whilst there was no one ICHOM standard set for a condition where HMV is a main treatment, in reviewing it gave us insight into outcomes which may cross over and also be key factors for HMV patients.

Patients' characteristics and outcomes were described overall and by pathology. For each outcome, factors influencing the choice of outcomes were selected in logistic regression procedure: disease, country and factors were assessed in a univariate logistic regression and gathered into a multivariable logistic regression when their pvalue with the outcome was below 0.20. A stepwise selection procedure was then applied to select the variables significantly associated with the outcome. Statistical analyses were performed using SAS version 9.4.

RESULTS

In total 3634 patients responded. 70% of patients completed the survey themselves whilst 30% were completed by their carer on their behalf. 1467 with Obesity Hypoventilation Syndrome, 1335 with Lung airway disease, 656 patients with Neuromuscular Disease, and 176 other diseases.



OHS (N=1,467)	Lung & Airway Disease (N=1,335)	NMD (N=656)
Being able to sleep well 83%	Being able to breathe well 92%	Being able to breathe well 90%
Being able to breathe well 82%	Being able to sleep well 57%	Being able to sleep well 59%
Feeling comfortable with the equipment 71%	Feeling comfortable with the equipment 53 %	Feeling comfortable with the equipment 51 %
Feeling safe while using the ventilator 52%	Being able to perform everyday activities 42%	Feeling safe while using the ventilator 44%
Being able to perform everyday activities 42%	Not having to call emergency service 42%	Not having to call emergency service 42%
Feeling in control of my treatment 30%	Feeling safe while using the ventilator 41%	Being able to communicate with people 31%
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The key finding was that at a global level the three most important outcomes are the same for all patients, although the level of importance of these varies by disease as do the other outcomes selected.

Patient Characteristics by disease type			Therapy usage by disease type		•		
	OHS (N=1467)	LUNG AIRWAY DISEASE (N=1335)	NMD (N=656)		OHS (N=1467)	LUNG AIRWAY DISEASE (N=1335)	NMD (N=656)
Male	1015 (69%)	729 (54%)	388 (59%)	Lenght of time on ventilator: 2 years +	1240 (84%)	987 (74%)	521 (79%)
Age : 18 - 24	20 (1.4%)	35 (3%)	81 (12%)	6 months - 2 years	171 (12%)	223 (17%)	81 (12%)
25-44	73 (5%)	51 (4%)	162 (25%)	Less 6 months	56 (4%)	125 (9%)	53 (8%)
45-64	561 (38%)	351 (26%)	202 (31%)	Time of day ventilator is used : Mostly during the night	1369 (93%)	937 (70%)	379 (58%)
65 +	813 (55%)	898 (67%)	211 (32%)	About the same day and night	87 (6%)	326 (24%)	248 (38%)
Live with someone/others	1167 (80%)	1079 (81%)	609 (93%)	Mostly during the day	10 (1%)	72 (5%)	29 (4%)
Receive nursing care	209 (14%)	522 (39%)	398 (61%)	Other Therapy: Oxygen	384 (26%)	965 (72%)	250 (38%)
Patient replied himself to survey	1258 (86%)	894 (67%)	329 (50%)	Aerosol therapy	80 (5%)	241 (18%)	58 (9%)
Time since diagnosis: 2 years +	1306 (89%)	1185 (89%)	587 (89%)	Suction device	41 (3%)	94 (7%)	186 (28%)
6 months - 2 years	133 (9%)	106 (8%)	49 (7%)	Cough assistance	22 (1%)	67 (5%)	190 (29%)
Less 6 months	28 (2%)	44 (3%)	20 (3%)	Tracheostomy	19 (1%)	72 (5%)	146 (22%)

Most of the patients were male (61%), aged more than 65 years (56%) were living with someone (83%) and did not receive nursing care (67%).

Influence of the therapy on outcome selection

Factors influencing the outcomes that matter to patients:





This large international survey has given a voice to the patients to understand the outcomes that matter to them.

This survey has identified the need for profiling of patients and the need to provide personalised care to help achieve treatment outcomes and patient best quality of life. In line with ICHOM methodology, results are now being discussed with patients, carers and Health Care Professionals to identify what needs to be improved in the patient care pathway and to build personalised care plans for patients who receive HMV. Segmentation methodology is also being built to enable personalised care to be provided to help patients based on their primary disease to achieve best quality of life.





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