심폐재활

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Survey of Burden of Caregivers of the Patients Using Home Mechanical Ventilator

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Objective

In recent years, with the development of home mechanical ventilator (HMV) technology, patients in need of ventilatory support have become cared at home. However, the HMV is uncomfortable, bulky, economically burdensome, and make great limitations on the lives of the patients and their caregivers. The purpose of this study is to investigate the burden of caregivers of community-dwelling patients using HMV through questionnaires.

Methods

A total of 136 patients using HMV and their caregivers or family members answered the questionnaire. The questionnaire is composed of 2 sections, each of which consisted of the status of patient care and the burden on caring. At the same time, the Korean version of Short Form Zarit Burden Interview (K-ZBI-12) and 3-Level version of EuroQol-5 Dimension (KEQ-5D-3L) were investigated to measure the burden on caring and the life quality of caregivers. The KEQ-5D-3L score was recalculated by the weighted formula for each item in the Korean population. Except for some missing portion, collected data were statistically analyzed.

Results

Demographics and descriptive data are shown in Table 1. Main caregivers were family members in 50 (37.9%), professional caregivers in 34 (25.8%) or both in 48 (36.4%) patients. Only one caregiver was taking care of the patients in 39 cases (29.5%). Caregivers responded that position change and patients' discomfort are one of the most burdensome for them. Majority of family members reported that more financial support and consumables are needed. More than half of the responders answered that patients' immobility, reduced free time and increased financial burden are the most difficult parts after using HMV. The detailed responses are listed in Table 2. The K-ZBI-12 score showed a weak negative correlation with KEQ-5D-3L score (p=0.000). Patients' age and financial burden from both medical and nursing cost also showed weak positive correlations with K-ZBI-12 scores (p=0.007, 0.000 and 0.000, respectively), but not with KEQ-5D-3L score. The more caregivers care for the patients, the lower K-ZBI-12 score (p=0.000). Caregivers who are caring the patients using invasive ventilation showed lower KEQ-5D-3L score than the others (p=0.001). Duration of HMV use and patients' weight affected neither K-ZBI-12 nor KEQ-5D-3L score (Table 3).

Conclusion

In this study, we looked at the needs of caregivers and family members of the patients using HMV. Life quality and care burden of the caregivers and family members were affected by various properties of the patients. We hope this study will help identify the institutional, economic and medical services, community-dwelling patients using HMV and their caregivers need.

Table 1. Demographics and analyzed data of the subjects

Variables (n=136)	Values
Sex	
Male	99 (72.8%)
Female	37 (27.2%)
Age (years)	53.82±17.49
Height (cm)	163.34±10.91
Weight (kg)	54.26±13.62
Body Mass Index (BMI)	20.18±4.31
Abdominal circumference (cm)	76.46±13.95
Diagnosis	
Neuromuscular disease	104 (76.5%)
Brain lesion	14 (10.3%)
Spinal cord injury	5 (3.7%)
Pulmonary disease	8 (5.9%)
ETC	5 (3.7%)
Marital status	
Single	37 (27.2%)
Married	93 (68.4%)
Divorced	6 (4.4%)

All parameters were analyzed using descriptive analysis except for some missing data due to some partial non-responders

Table 2. Status of caring and burdens felt by caregivers of patients using HMV

Variables (n=136)	Values
Who is the main caregiver?	
Family member	51 (37.5%)
Professional caregiver	36 (26.5%)
Both	49 (36.0%)
How many caregivers are caring the patient?	
One	40 (29.4%)
More than one	96 (70.6%)
What is the most burdensome part of using HMV?	
Difficulty of changing patients' position	81 (59.6%)
Patients' complaint from discomfort	62 (46.3%)
Immobility due to HMV	32 (23.5%)
Noise from HMV	22 (16.2%)
Frequent pulmonary infection	12 (8.8%)
Difficulty of using HMV	9 (6.6%)
HMV-induced accidents	1 (0.7%)
What is support do you need while using HMV?	
Financial support	86 (63.2%)
Periodic replacement of consumables	64 (47.1%)
Support in patient care (mobility, position change, sanitization)	50 (36.8%)
Regular visits of HMV specialists and medical providers	40 (29.4%)
Education about using HMV	23 (16.9%)
What has become more difficult since the patient started using HMV? (n=117)	
Decreased mobility of patients	72 (61.5%)
Reduced free time	68 (58.1%)
More financial burden	64 (55.2%)
Difficulty of patients' pulmonary care	39 (33.3%)
Not changed	20 (17.1%)
Noise from HMV is annoying	15 (12.8%)
More emergent situations	8 (6.8%)
Difficulty of using HMV	6 (5.1%)
How much financial burden do you feel for patients' medical expenses?*	2.56±0.84
How much financial burden do you feel for patients' nursing cost?*	2.53±0.91

All parameters were analyzed using descriptive analysis except for some missing data due to partial non-responders. Items indicated with asterisk (*), which are Likert scale ranging from 1 (not at all) to 4(very much), are described by Mean±SD. The items for difficulties and required supports while using HMV allowed multiple responses.
HMV, home mechanical ventilator

Table 3. Scores of K-ZBI-12 and EQ-5D-3L according to characteristics of patient caring

Variables		Values (n=113)	
		K-ZBI-12	KEQ-5D-3L
Total	Mean±SD	31.28±11.75	0.75±0.25
	rho	-0.325	
	p-value	0.000*	
Age	rho	0.245	-0.134
	p-value	0.009*	0.157
Weight	rho	-0.032	0.095
	p-value	0.750	0.343
Duration of HMV use	rho	-0.184	-0.027
	p-value	0.070	0.780
Financial burden of medical expenses (from item in Table 2)	rho	0.438	-0.148
	p-value	0.000*	0.118
Financial burden of nursing cost (from item in Table 2)	rho	0.487	-0.193
	p-value	0.000*	0.070
Number of caregivers	Only one	24.77±9.20	0.79±0.22
	More than one	34.21±11.63	0.73±0.26
	p-value	0.000*	0.205
Type of ventilation	Invasive ventilation	32.89±12.62	0.70±0.28
	NIV	28.95±8.83	0.84±0.17
	p-value	0.059	0.001*

All parameters were analyzed using descriptive analysis except for some missing data due to partial non-responders. The K-ZBI-12 consists of 12 items which are Likert scale ranging from 0 (not at all) to 4(always). The items of EQ-5D-3L is recalculated by weighted formula for Korean population, ranging from -0.171 to 1.

K-ZBI-12, Korean Version of Short Form Zarit Burden Interview; KEQ-5D-3L, Korean version of 3-level version of EuroQol-5 Dimension; HMV, home mechanical ventilator

Asterisk (*) means statistically significant