

RESEARCH ARTICLE

Factors associated with caring behaviors of family caregivers for patients receiving home mechanical ventilation with tracheostomy: A cross-sectional study

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Abstract

Background

The number of patients on home mechanical ventilation (HMV) worldwide has been steadily rising as medical technological advanced. To ensure the safety and quality care of the patients receiving HMV with tracheostomy, caring behavior of family caregivers is critical. However, studies on caring behavior of family caregivers and its associated factors were remained unexplored. This study aimed to describe the caring behaviors of family caregivers for patients receiving home mechanical ventilation with tracheostomy and to identify factors associated with their caring behaviors.

Methods

This was a cross-sectional study for 95 family caregivers for patients with invasive home mechanical ventilation in South Korea. Caring behaviors were assessed by the Caring Behavior Scale with 74 items with 5-point Likert scale. Data were analyzed using multiple regression analysis.

Results

Caring behaviors score of caregivers was 304.68±31.05 out of 370. They were significantly associated with knowledge on emergency care ($\beta = 0.22, p = .011$), number of required instruments for care ($\beta = 0.21, p = .010$), frequency of home visit care ($\beta = 0.19, p = .017$), experience of emergency situation for the last six months ($\beta = 0.19, p = .009$) and activities of daily living of patient ($\beta = 0.27, p = .002$).

Conclusion

Development of standardized multidisciplinary discharge education for improving the caring capacity of caregivers is required for successful and healthy application of home mechanical ventilation.

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Introduction

The number of patients on home mechanical ventilation (HMV) worldwide has been steadily rising as medical technological advanced [1]. HMV is a medical treatment for long-term breathing support for patient who cannot keep their airway patent by themselves but need to be discharged from the emergency setting, such as patients with neuromuscular diseases or respiratory problems [1]. HMV is administered as either invasive positive pressure ventilation (IPPV), which involves a tracheostomy, or noninvasive positive pressure ventilation (NIPPV), which uses a mask or nasal intubation [2]. HMV with tracheostomy is generally administered 24 hours a day (i.e., much longer than for NIPPV) [3]. As a result of the characteristics of the treatment and their illnesses, patients receiving HMV with tracheostomy have limited physical activity, which makes them highly dependent on caregivers [4].

The global prevalence of HMV was reported to be 6.6–23 per 100,000 people [1]. In South Korea, HMV prevalence has also gradually increased, reaching 9.3 per 100,000 people in 2017 [5]. Recently, 83.3% of patients decided to be discharged with home mechanical ventilation after finishing acute care in South Korea [6,7]. It is mainly for spending time at home to maintain quality of life for both family and patients [8,9] and to lessen the burden of health-care costs [10]. It is also partly related to the South Korea's National Health Insurance Service, which was broadened its scope to the use of HMV to cover pulmonary diseases and cardiac diseases with chronic respiratory symptoms in 2016 [11]. However, the readmission rate of patients with HMV was as high as 60%, with many of these cases returned to ICUs due to the worsened or emergency situations [12]. Patients with long-term HMV with tracheostomy showed higher readmission rates than NIPPV patients [13] and the cause of their readmission was associated with safety issues with HMV in 76% of cases [13]. Consequently, to ensure the safety of the patients receiving HMV with tracheostomy, family caregivers' awareness of emergency situations, coping skills, and ability to manage equipment play key roles [14].

To improve caregivers' competencies for dealing with safety issues of patients on HMV with tracheostomy, specialized education programs are needed as home-based caregivers are required not only to meet patients' physical needs but also to perform nursing tasks such as inner cannula change, airway secretion suctioning, and positive pressure ventilation using an Ambu-bag [15]. Current pre-discharge caregiver education in Korea is provided without a prior plan, mostly by ventilator rental company employees using leaflets [16]. Moreover, caregiver education is focused mainly on the skills required for home ventilator management, not on communication with patients who are unable to speak and rehabilitation of those who are bedridden [17]. Thus, the education caregivers currently receive is insufficient for them to acquire the necessary skills to independently deliver safe care for patients [18].

Many previous studies conducted identified knowledge on emergency care of caregivers of patients receiving HMV with tracheostomy [19], frequency of caregivers' caring behaviors [20], family caregivers' caring experience for patients with HMV, the burden of caring behaviors, and quality of life of caregivers [21,22], and the correlation between airway suctioning and the occurrence of pneumonia [23]. Studies on associated factors of caring behaviors of caregivers were remained unexplored. Therefore, this study aimed to identify the factors that affect the caring behaviors of family caregivers of patients receiving HMV with tracheostomy, and to suggest interventions for improving their care performance.

Materials and methods

Study design and participants

This is a descriptive, cross-sectional study to explore the caring behaviors of family caregivers for patients on HMV with tracheostomy, and to determine the factors associated with these caring behaviors. The participants in this study were family caregivers who provided home-based care for at least six hours a day to patients receiving HMV with tracheostomy. Participants were approached by home visit nurses using the client list of the ventilator rental company based in Seoul, Korea. The inclusion criteria were: 1) aged equal to or greater than 19 years old and having a family relationship with the patient, such as a spouse, parent, or child (including daughter-in-law and son-in-law); and 2) living with the patient and providing primary, unpaid care. Caregivers of patients with NIPPV or impaired cognitive and physical functions were excluded.

Measures

Characteristics of the participants. The questionnaires on participants' general characteristics was developed based on a previous study that investigated the association between the features of care provided by family caregivers and the burden they experience [21]. The general characteristics of interest included gender, age, and education level were assessed. Care related variables included discharge education experience, experience of emergency situations for the last six months, satisfaction with home visit care, preparedness of required equipment for emergency situations, and difficulties in caring patients. Additionally, an open-ended question was added to describe participants' experiences with ventilator-related emergency situations (S1 File).

Knowledge of emergency care of caregivers was assessed using the Korean version of the Knowledge of Emergency Care Scale developed by Hwang et al. [17] (S1 File). It was originally developed by Kun et al. [19] to measure the capability of emergency care and response which should be possessed by primary caregivers of patients receiving HMV with tracheostomy. Permission to use this tool was obtained from the original author and also from the author who developed the Korean version. It consists of five categories with 25 items: aspiration management (4 items), routine management of tracheostomy tubes (6 items), ventilator management (5 items), management when the tracheostomy tube is decannulated (5 items), and basic cardiopulmonary resuscitation (5 items). One point is awarded for correct answers and zero point for incorrect answers; thus, the total score range is 0–25, with higher scores indicating higher knowledge level. Cronbach's α of the original questionnaire was .91 [17], while it was .95 in this study.

Characteristics of the patients. Patient information included general characteristics, disease manifestations such as diagnosed disease, level of physical dependency, HMV-related information (i.e., duration, ventilator mode, use of oxygen, application hour per day), frequency of home visit care, and activities of daily living (ADLs). Their ADLs were evaluated using a 12-item scale, which indicates patient dependency on caregivers (S2 File). Each item of ADLs was scored using a three-point Likert scale (1 = "can do it alone," 3 = "totally depends on help"); thus, total scores ranged from 12 to 36 points. Higher summed score means lower level of ADLs which indicates higher dependency on their caregivers [24]. Cronbach's α in this study was .95.

Caring behaviors. Caring behaviors of the caregivers were measured using the Caring Behavior Scale developed by Hwang et al. [21] after gaining a permit to use. It comprises 10 categories with 74 items: HMV management (14 items), airway management (11 items),

nutrition management (10 items), rehabilitation exercise (3 items), personal hygiene (6 items), commodity management (4 items), environmental management (4 items), communication (2 items), psychological nursing (2 items), and aspiration management (18 items). Items were scored by a five-point Likert scale (1 = “not at all,” 5 = “always”) (S3 File). The higher summed score means the higher ability to provide care. Cronbach’s α of the original questionnaire was .91 [17], while it was .90 in this study.

Ethics statement

This study was approved by the institutional review board of the Yonsei University Health system, Severance Hospital (# 4-2019-0230) where the researchers were working. Home visit nurses affiliated with the ventilator rental company conducted in-person data collection from family caregivers of patients receiving HMV with tracheostomy. During the home visits, nurses provided detailed information of the study and caregivers freely decided their participation. Caregivers were informed that their participation or refusal would never related to home visit care. The research was conducted only with caregivers who provided written informed consent. A small gift was given to all participants when they finished the questionnaires.

Data collection process

Data were collected from May to July 2019 using self-report questionnaires. Five home visit nurses working for the ventilator rental company collected the data during their home visits. The home visit nurses had 2-hour training for data collection prior to starting the survey. The home visit nurses explained the purpose, methods, and procedures of the study to the caregivers and obtained informed consents. The nurses also provided supports for family caregivers who were illiterate or had problems with seeing vision by reading the questions and recording the responses. Based on the sample size estimated for multiple linear regression analysis with a 10% dropout rate, 130 caregivers were initially approached, with questionnaires distributed to the 100 who agreed to participate. Of these 100, after excluding the questionnaires of five caregivers whose responses were insufficient, the data of 95 caregivers were analyzed.

Statistical analysis

The data (S4 File) were analyzed using the SAS 9.4 program. Frequencies and percentages, and means and standard deviations were used for descriptive analysis. Differences between groups were compared using independent *t*-tests and analyses of variance followed by the post-hoc multiple comparison. Correlations between continuous variables and care behaviors were analyzed using Pearson’s correlation coefficients. The factors associated with care behaviors of the family caregivers were identified by multiple regression analysis, and the variables for final regression model were selected by the backward selection method.

Results

Characteristics of family caregivers

A total of 95 family caregivers participated. The mean age of the family caregivers was 51.02 (\pm 10.85) years. Out of 95 participants, 71 (74.7%) were female, and 78 (82.1%) were married. In terms of education level, 56 (59.0%) participants were graduated from their college. Regarding the relationship with their patient, 54 (56.8%) caregivers were parents, and 28 (29.5%) were spouses of patients. Seventy-eight (82.1%) participants were unemployed, and 35 (36.8%) reported that the monthly household income was over 3 million Korean Won (1,000 Korean Won = \$1), and 19 (20.0%) reported that they earned less than 1 million Korean Won per

month. Regarding care-related characteristics, 85 (89.5%) reported that they had care-related education in the hospital at the time of the patient's discharge. The mean number of home visit nursing care per month was 1.12 (\pm 0.86). Eighty-seven (91.6%) responded that they had no experience of emergency situations for the last six months. The mean knowledge level on emergency care was 20.64 (\pm 2.14) out of 25, and the mean score for Satisfaction with Medical Service was 5.24 (\pm 2.68) out of 10 (Table 1).

Characteristics of patients

The mean age of the patients was 38.08 (\pm 26.2) years old, this relatively low mean age was owing to the inclusion of 30 children in the sample. Of the 95 patients, 65(68.4%) were male. Regarding underlying diseases, 67 (70.5%) patients had neuromuscular diseases while 15 (15.8%) had respiratory diseases. Among 95 patients, 33 (34.7%) had been on HMV for 3–4 years, 28 (29.5%) for less than three years, 19 (20.0%) for 5–10 years, and 15 (15.8%) for more than 10 years. Regarding the modes of HMV, 70 (73.7%) were on pressure-controlled ventilation (PCV) and 25 (26.3%) on volume-controlled ventilation (VCV). Among 95 patients; 34 (35.8%) used oxygen. The mean hour of daily HMV usage was 21.34 (\pm 6.16), and patients' physical dependency (i.e., the ADL scale) was 22.47 (\pm 4.02). The average required equipment was 12.73 \pm 1.4; this included an Ambu bag, oxygen monitor, blood pressure monitor, thermometer, spare cannula and circuit, cough inducer, extra battery, and extra portable suction machine, which were needed in case of emergency at home. Characteristics of the patients are presented in Table 2.

Table 1. General characteristics of family caregivers (n = 95).

Characteristics	Categories	n (%)	Mean \pm SD
Age (years)			51.02 \pm 10.85
Sex	Female	71 (74.7)	
	Male	24 (25.3)	
Marital status	Married	78 (82.1)	
	Unmarried	12 (12.6)	
	Others	5 (5.3)	
Educational level	\leq High school	39 (41.1)	
	\geq College	56 (59.0)	
Employment status	Yes	17 (17.9)	
	No	78 (82.1)	
Monthly income (Korean Won)	<1 million	19 (20.0)	
	1–<2 million	21 (22.1)	
	2–<3 million	20 (21.1)	
	\geq 3 million	35 (36.8)	
Relationship with patients	Spouse	28 (29.5)	
	Parents	54 (56.8)	
	Others	13 (13.7)	
Education for discharge care	Yes	85 (89.5)	
	No	10 (10.5)	
Experience of emergency situation (within 6 months)	Yes	8 (8.4)	
	No	87 (91.6)	
Knowledge on emergency care(0–25)			20.64 \pm 2.14

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Table 2. General and disease-specific characteristics of patients (n = 95).

Characteristics	Categories	n (%)	Mean±SD
Age (years)			38.08±26.62
Sex	Male	65 (68.4)	
	Female	30 (31.6)	
Primary disease	Neuromuscular	67 (70.5)	
	Lung/Airway	15 (15.8)	
	Others	13 (13.7)	
Duration of HMV ^a	<3years	28 (29.5)	
	3–4years	33 (34.7)	
	5–9years	19 (20.0)	
	≥10years	15 (15.8)	
Ventilator mode	Volume control	25 (26.3)	
	Pressure control	70 (73.7)	
O ₂ usage	Yes	34 (35.8)	
	No	61 (64.2)	
HMV ^a application hours/day			21.34± 6.16
Number of home visits/month			1.12± 0.86
^b ADL			22.47±4.02
Number of required equipment			12.73±1.4

^aHMV = home mechanical ventilator,

^bADL = activities of daily living.

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Caring behaviors of family caregivers

The overall summed score of the caring behaviors was 304.68 (± 31.05) out of 370. Caring behavior of ventilator management was 61.94 (±6.94) out of 70 while airway management was 48.04 (±5.70) out of 55. Nutritional support was scored at 37.93 (±17.03) out of 50, rehabilitation 7.84 (±3.34) out of 15, and the personal hygiene 26.54 (±3.56) out of 30. Equipment management was scored at 18.55 (±2.26) whereas environmental management was 19.01 (±1.96) out of 20. Communication with patients was scored at 6.43 (±3.02) out of 10. Suctioning showed 78.36 (±7.14) out of 90 (Table 3).

There was no significant difference of care behaviors according to the general characteristics of family caregivers (Table 4).

Table 3. Caring behavior scores of family caregivers.

Categories	Mean±SD	Min	Max
Total caring behavior	304.68±31.05	72	370
Ventilator management	61.94±6.94	14	70
Airway management	48.04±5.70	11	55
Nutrition support	37.93±17.03	10	50
Rehabilitation	7.84±3.34	3	15
Personal hygiene	26.54±3.56	6	30
Equipment management	18.55±2.26	4	20
Environmental management	19.01±1.96	4	20
Communication	6.43±3.02	2	10
Suction	78.36±7.14	18	90

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Table 4. Difference of caring behavior scores by characteristics of family caregivers.

Characteristics	Categories	Caring behaviour		
		Mean±SD	t or F	p-value
Sex	Male	298.29±31.54	1.37	.245
	Female	306.85±30.80		
Marital status	Married	311.83±24.00	1.55	.218
	Unmarried	302.33±32.46		
	Others	324.20±6.69		
Educational level	≤High school	309.10±33.84	1.34	.249
	≥College	301.61±28.85		
Employment status	Yes	308.59±29.99	0.33	.570
	No	303.83±31.40		
Monthly income (Korean Won)	<1 million	296.68±33.42	1.26	.293
	1–<2 million	315.14±24.52		
	2–<3 million	302.80±35.12		
	≥3 million	303.83±30.40		
Relationship	Spouse	305.36±34.57	1.15	.320
	Parents	301.59±31.45		
	Others	316.08±17.52		
Education for discharge care	Yes	304.87±31.36	0.03	.866
	No	303.10±26.78		
Experience of emergency (within 6 months)	Yes	322.63±18.39	2.98	.088
	No	303.03±31.52		

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Factors associated with caring behaviors of family caregivers

To determine the factors predicting caring behaviors of caregivers, independent variables were selected based on the previous studies. In the final model of analysis, caregiver characteristics (i.e., caregiver variables of knowledge on emergency care, frequency of home nurse visits, preparedness to use required equipment during emergency situations, and experience of emergency situations for the last six months) and patients' disease-specific characteristics (i.e., ADL, primary disease, and the number of required equipment) were included. Age and gender of caregivers were adjusted in the model.

The final multiple regression analysis showed that the explanatory power was 48.4%. The results showed that higher patient ADL, higher caregiver knowledge on emergency care, higher preparedness to use required equipment during the emergency situations, greater number of home visits, and having experience of emergency situations within the past six months were significantly associated with the higher caring behaviors of family caregivers (Table 5).

Discussion

This study aimed to estimate the caring-behavior levels of family caregivers of patients receiving HMV with tracheostomy after hospital discharge, and also sought to obtain basic data that could inform the development of nursing education programs for reducing home caregivers' burden. The results showed that the caring behavior of caregivers were associated with ADL of patient, knowledge on emergency care, preparedness of equipment for emergency situations, and experience of emergency situations.

The study results presented that the family caregivers' characteristics were not significantly associated with the caring behaviors of caregivers, which caregivers provided on a regular

Table 5. Factors associated with caring behaviors of family caregivers.

Variables	B	SE	β	t	p-value
Age	2.05	0.63	0.27	3.24	.002
Knowledge on emergency care	3.15	1.21	0.22	2.59	.011
Number of home visits per month	6.77	2.77	0.19	2.44	.017
Emergency experience (ref: No)					
Yes	20.58	8.67	0.19	2.37	.009
ADL ^a of patients	2.05	0.63	0.27	3.24	.002
Number of required equipment	4.63	1.77	0.21	2.62	.010

^aADL: Activities of daily living.

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basis. Notably, however, the provision of respiratory rehabilitation care was not sufficient, although a previous study reported that respiratory rehabilitation at home is effective for increasing exercise capacity and quality of life [25]. In other research on respiratory rehabilitation in the home, the use of medical equipment such as cough assists, postural drainage, and patient monitoring with pulse oximetry accounted for only 18%, 13.6%, and 16%, respectively, of the care provided [26]. In this study, preparedness of required equipment was associated with a higher level of caring behaviors; thus, assessment of equipment preparedness on discharge and connection of home-based respiratory rehabilitation with home visiting care are needed to improve care at home and help reduce patients' length of hospitalization.

The scores for the family caregivers' knowledge on emergency care was lower than those reported in one previous study [19], but higher than those reported in studies of patients with ALS [17]. This difference may be due to the duration that care was provided, resulting in different levels of knowledge and education over time. However, given the duration of time that our participants had been provided care, we considered that the proportion who had sufficient knowledge to provide appropriately safe care was low [19]. The element of knowledge of emergency care for which the participants scored highest was ventilator management, while the lowest-scoring element was airway suction. The participants' score for airway clearance technique was similar to that reported in previous surveys [19]. In contrast, we found that our participants' ventilator management scores were high. A possible reason for this is that education on ventilator equipment is provided on a regular basis by the rental agent, and an agent is available for consultation via phone at any time of the day or night. Thus, the contents of the education that is provided by rental agents and of the education provided at hospitals at patient discharge should be examined and integrated into operational systems for patient management.

When caring for patients receiving HMV with tracheostomy, airway cleaning techniques and the ability to recognize and manage emergency situations are particularly important [19]. However, previous studies have reported that only 48% of caregivers feel prepared at the time of discharge [27], and a Korea-based study reported that 31% of caregivers do not receive education at patients' initial discharge [28]. In this survey, over 89.5% of the participants received a ventilator care education program offered by the rental agent. One study showed that education regarding providing care for patients receiving HMV with tracheostomy commences immediately after they undergo tracheostomy, and is performed by a multidisciplinary team comprising physicians, nurse practitioners, rapid response teams, social workers, and home health nurses [27]. In particular, the provision of education on emergency situations needs to be based on realistic clinical scenarios, while discharge education must be rooted in the practical needs of family caregivers, including how to properly communicate with patients and

support their long-term rehabilitation. In contrast, in South Korea the main teaching methods include oral presentation and printed handouts, and limited demonstrations of how to provide care for patients using ventilators are performed during rental agent visits; thus, caregivers in South Korea do not receive video-based education. This indicates that a more organized discharge process is needed, including a standardized discharge program and the utilization of various teaching methods at the hospital. In addition, policies for providing safe and efficient home health services should be established for family caregivers of patients receiving HMV with tracheostomy, in terms of supporting hospitalization, mobility, and payment schemes.

This study has several limitations. First, it only considered family caregivers of patients receiving HMV with tracheostomy who were living in the capital city of Seoul and a metropolitan city of Gyeonggi Province, which may affect the generalizability of the findings. Second, this study focused only on determining the extent to which knowledge of emergency situations and general characteristics affect family caregivers' caring behaviors and the level of care they provide. Future research should consider numerous additional variables, such as burdens influencing care level and quality of life, and also include qualitative evaluations of family caregivers' actual caring skills by nurses. Third, the number of patients who had experienced an emergency situation was relatively small, although it turned out to be a statistically meaningful factor in a previous study [29] and this study. Future studies should evaluate the effect of emergency situation experience in larger patient groups. Lastly, there is a possibility of discrepancies between self-reported and actual caring behaviors; thus, there is a need for studies exploring the correlation between family caregivers' self-reports of their care performance and their actual performance.

Conclusions

Development of standardized multidisciplinary discharge education for improving the caring capacity of caregivers is required for successful and healthy application of home mechanical ventilation. Realistic and specific clinical scenario-based education should be provided to family caregivers right from the time of patients' hospital admission. In addition, it is necessary to create comprehensive and consistently available home health services that are affiliated with home-visit nurses and community resources and are available to caregivers after discharge.

Supporting information

S1 File. Emergency knowledge questionnaire.

(PDF)

S2 File. ADL of patient questionnaire.

(PDF)

S3 File. Caring behaviour questionnaire.

(PDF)

S4 File. Data set.

(PDF)

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References

1. Rose L, McKim DA, Katz SL, Leasa D, Nonoyama M, Pedersen C, et al. Home mechanical ventilation in Canada: A national survey. *Respiratory Care*. 2015; 60:695–704. <https://doi.org/10.4187/respcare.03609> PMID: 25587173
2. Ambrosino N, Vitacca M. The patient needing prolonged mechanical ventilation: A narrative review. *Multidisciplinary Respiratory Medicine*. 2018; 13:6. <https://doi.org/10.1186/s40248-018-0118-7> PMID: 29507719
3. Bodenham A, Bell D, Bonner S, Branch F, Dawson D, Morgan P, et al. Standards for the care of adult patients with a temporary tracheostomy; Standards and guidelines. Intensive Care Society. 2014.
4. Kim MH, Kim HS, Park JD. Factors influencing readmission of home ventilator-assisted children. *Journal of Korean Academy of Child Health Nursing*. 2012; 18:9–18.
5. Kim HI, Cho JH, Park SY, Lee YS, Chang Y, Choi WI, et al. Home mechanical ventilation use in South Korea based on national health insurance service data. *Respiratory Care*. 2019; 64:528–35. <https://doi.org/10.4187/respcare.06310> PMID: 30584068
6. Lee MK, Song CR, Oh EK, Yoon YM. A survey of hospital-based home healthcare utilization in patients using home mechanical ventilator. *Journal of Home Nursing*. 2017; 24:210–20.
7. Mun SW, Kim HY, Kim HY, Park HJ, Kim SY, Shin YB, et al. A study of the use of home mechanical ventilation and medical insurance. *Allergy Asthma & Respiratory Disease*. 2016; 4:195–8.
8. Lopez-Campos JL, Failde I, Masa JF, Benitez-Moya JM, Barrot E, Ayerbe R, et al. Factors related to quality of life in patients receiving home mechanical ventilation. *Respiratory Medicine*. 2008; 102:605–12. <https://doi.org/10.1016/j.rmed.2007.11.005> PMID: 18068344
9. Povitz M, Rose L, Shariff SZ, Leonard S, Welk B, Jenkyn KB, et al. Home mechanical ventilation: A 12-year population-based retrospective cohort study. *Respiratory Care*. 2018; 63:380–7. <https://doi.org/10.4187/respcare.05689> PMID: 29208755
10. Marchese S, Lo Coco D, Lo Coco A. Outcome and attitudes toward home tracheostomy ventilation of consecutive patients: A 10-year experience. *Respiratory Medicine*. 2008; 102:430–6. <https://doi.org/10.1016/j.rmed.2007.10.006> PMID: 18023334
11. Ministry of Health and Welfare. Partial amendments to insurance benefit standards and methods of medical care expenses [Internet]. Seoul: Ministry of Health and Welfare; 2016 [cited 2019 May 27]. <http://www.mohw.go.kr>.
12. Rose L, Watling L, Kohli R, Bautista C, Renzetti D, Avendano M, et al. Transition program for ventilator assisted individuals from acute care to home. *Canadian Journal of Respiratory, Critical Care, and Sleep Medicine*. 2019; 3:100–5.
13. Simonds AK. Home mechanical ventilation: An overview. *Annals of the American Thoracic Society*. 2016; 13:2035–44. <https://doi.org/10.1513/AnnalsATS.201606-454FR> PMID: 27560387
14. Evans R, Catapano MA, Brooks D, Goldstein RS, Avendano M. Family caregiver perspectives on caring for ventilator-assisted individuals at home. *Canadian Respiratory Journal*. 2012; 19:373–9. <https://doi.org/10.1155/2012/452898> PMID: 23248801

15. Brooks D, Gibson B, DeMatteo D. Perspectives of personal support workers and ventilator-users on training needs. *Patient Education and Counseling*. 2008; 71:244–50. <https://doi.org/10.1016/j.pec.2008.01.018> PMID: 18325719
16. Ahn JJ, Lee KM, Shim TS, Lim CM, Lee SD, Kim WS, et al. Survey of Current Status of the Patients with Home Ventilator in Seoul and Kyunggi Province. *Tuberculosis and Respiratory Diseases*. 2000; 49(5):624–632. <https://doi.org/10.4046/trd.2000.49.5.624>
17. Hwang MS, Park JH. Pneumonia incidence varies by tracheal suction procedures among caregivers of patients with home mechanical ventilations. *Journal of Korean Academic Society of Home Health Care Nursing*. 2016; 23:25–33.
18. Mallory L. A., Osorio S. N., Prato B. S., DiPace J., Schmutter L., Soung P., et al. (2017). Project IMPACT pilot report: feasibility of implementing a hospital-to-home transition bundle. *Pediatrics*, 139(3), e20154626. <https://doi.org/10.1542/peds.2015-4626> PMID: 28202769
19. Kun SS, Davidson-Ward SL, Hulse LM, Keens TG. How much do primary care givers know about tracheostomy and home ventilator emergency care? *Pediatric Pulmonology*. 2010; 45:270–4. <https://doi.org/10.1002/ppul.21169> PMID: 20146395
20. Karaca T, Altinbas Y, Aslan S. Caring for patients with a tracheostomy at home: a descriptive, cross-sectional study to evaluate health care practices and caregiver burden. *Wound Management & Prevention*. 2019; 65:22–9. PMID: 30986200
21. Hwang MS, Lee MK, Song JR. The factors affecting burdens and quality of life of the family caregivers of patients with rare and incurable diseases using home ventilators. *Korean Journal of Adult Nursing*. 2014; 26:191–202.
22. Oh J, An JW, Oh KW, Oh SI, Kim JA, Kim SH, et al. Depression and caregiving burden in families of patients with amyotrophic lateral sclerosis. *Journal of Korean Academy of Nursing*. 2015; 45:202–10. <https://doi.org/10.4040/jkan.2015.45.2.202> PMID: 25947182
23. Hwang MS, Lee MK, Song JR. Effects of a home respiratory management program for patients with amyotrophic lateral sclerosis. *Korean Journal of Adult Nursing*. 2017; 29:406–18.
24. Morris JN, Fries BE, Morris SA. Scaling ADLs within the MDS. *The Journals of Gerontology. Series A* 1999; 54:M546–53. <https://doi.org/10.1093/gerona/54.11.m546> PMID: 10619316
25. Wijkstra PJ, Strijbos JH, Koëter GH. Home-based rehabilitation for patients with COPD: Organization, effects and financial implications. *Monaldi Archives for Chest Disease*. 2000; 55:130–4. PMID: 10949874
26. Kim DH, Kang SW, Choi W, Moon JH, Baek JH, Choi SH, et al. A research on the management of ventilatory insufficiency in patients with neuromuscular diseases. *Journal of the Korean Academy of Rehabilitation Medicine*. 2010; 34:347–54.
27. McCormick ME, Ward E, Roberson DW, Shah RK, Stachler RJ, Brenner MJ. Life after tracheostomy: Patient and family perspectives on teaching, transitions, and multidisciplinary teams. *Otolaryngology–Head and Neck Surgery*. 2015; 153:914–20. <https://doi.org/10.1177/0194599815599525> PMID: 26286873
28. Hwang MS, Chang SJ. Self-care education experience, self-care performance, and home care service needs of patients with rare and incurable diseases who use a home ventilator. *Journal of Korean Academic Society of Home Health Care Nursing*. 2012; 20:5–15.
29. Kim SO, Kim SY. Experience of emergency situation and experience of education, first aid knowledge and educational needs of caregivers. *Journal of Korean Public Health Nursing*, 2018; 32:288–303.