

11. Any visits to hospitals for problems associated with H MV or patient's condition during the last year?

11-1) Visit to outpatient office Yes No

11-2) Visit to emergency department: Yes No

12. Any hospitalizations for problems associated with H MV or patient's condition?

12-1) Hospitalization: Yes No

12-2) Admission to the ICUs: Yes No

13. National Health Insurance Service (Check only one)

National Health Insurance , Medical aid , Others:

14. How much do you pay per month (for out-of-pocket expenses associated with patient's care)

_____ Korean won/month

15. Any comments?

→

Thank you for answering this questionnaire.

Case Report Form 2
 Survey on home mechanical ventilator use in South Korea
 (Parameters associated with ventilator machines)

Patient Number: □□□ - □□□

1. Primary diagnosis (indication) for the use of home mechanical ventilation (HMV).

1-1) Diagnosis:

1-2) ICD-10 code 1) 2) 3)

2. What is the brand name of the home ventilator?

(this is to distinguish between life-support and non-life-support ventilators)

3. Daily hours on HMV

24-h use (full-day use)

Part-time use (hours/day)

4. Type of interfaces (masks)

Facial mask Nasal mask Nasal pillow 기타 :

5. Type of circuits

Single-limb circuit with a leak valve (an exhalation port)

Single-limb circuit with an exhalation valve

Double-limb circuit

6. Ventilator settings.

Mode	Oxygen supplied	IPAP	EPAP	Tidal volume	호흡수 (set RR)	I:E ratio
	(l/min)			ml		
Leak						
L/min						

Thank you for answering this questionnaire.

Table S1 Primary diagnosis for HMV use

Primary diagnosis	Adults (n=38), n (%)	Children (n=26), n (%)
Chronic obstructive pulmonary disease	14 (36.8)	0 (0.0)
Pulmonary arterial hypertension	1 (2.6)	1 (3.8)
Kyphoscoliosis	3 (7.9)	1 (3.8)
Central sleep apnea	2 (5.3)	0 (0.0)
Cerebrovascular diseases		
Cerebrovascular accident	2 (5.3)	0 (0.0)
Hypoxic brain damage	0 (0.0)	1 (3.8)
Neuromuscular disorders		
Amyotrophic lateral sclerosis	3 (7.9)	0 (0.0)
Mitochondrial myopathy	1 (2.6)	4(15.4)
Congenital myopathy	0 (0.0)	1 (3.8)
Genetic disorders		
Mucopolysaccharidosis type I	0 (0.0)	1 (3.8)
Gaucher's disease	0 (0.0)	1 (3.8)
Pompe disease	1 (2.6)	0 (0.0)
Rett syndrome	1 (2.6)	0 (0.0)
Congenital respiratory disorders		
Bronchopulmonary dysplasia	0 (0.0)	3 (11.5)
Malformations of trachea and bronchus	0 (0.0)	2 (7.7)
Unspecified respiratory disorder	7 (18.4)	7 (26.9)
Unspecified encephalopathy	3 (7.9)	4 (15.4)

HMV, home mechanical ventilation.

Table S2 Emergences incidents associated with HMV use at home[†]

Incidents	Numbers
Dyspnea (tachypnea)	17
Pneumonia	8
Tracheostomy obstruction	3
Tracheostomy dislocation	1
PEG malfunction	3
Hypoxemia	2
Copious secretion	1
Arrhythmia	1
High fever	1
Syncope	1
Seizure	2
Ventilator alarm	2

[†], a total of 42 incidents occurred in 28 patients during the last 1 year. HMV, home mechanical ventilation; PEG, percutaneous endoscopic gastrostomy.

Table S3 Data on 9 subjects who died while receiving HMV

No	Age (years)	Primary diagnosis for HMV	Duration of HMV (months) [†]	Interface	Cause of death
1	84	Unspecified respiratory disorder	23.0	Nasal mask	Disease progression
2	77	COPD	52.0	Facial mask	Disease progression
3	81	COPD	9.0	Tracheostomy	Disease progression
4	49	Unspecified respiratory disorder	17.0	Facial mask	Disease progression
5	70	Unspecified respiratory disorder	4.0	Tracheostomy	Unexpected
6	66	NMD	19.0	Tracheostomy	Disease progression
7	68	CSA	24.0	Tracheostomy	Disease progression
8	17	Unspecified respiratory disorder	7.0	Tracheostomy	Unexpected
9	7	Unspecified encephalopathy	32.0	Tracheostomy	Unexpected

[†], at the time of death. COPD, chronic obstructive pulmonary disease; CSA, central sleep apnea; HMV, home mechanical ventilation; NMD, neuromuscular disorder.