

## Peer Review File

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### Reviewer A

Comment 1. This was a cross sectional study exploring characteristics of and treatment facilities for 64 patients with long-term mechanical ventilation discharged from 3 university-affiliated hospitals in South Korea. The authors identifies a patient group with large need of support from the health care system and discuss the utopia of introducing a national quality registry as a tool to monitor and improve the care of these patients. This is a very important issue. The structure of this study has however several weaknesses.

Reply 1: Thank you for your comments.

Comment 2. The aim of the study was to “categorize the present status of HMV use”. Children and adults with HMV differ totally in clinical presentation but throughout the paper frequencies between children and adults are compared and p-values are presented. This comparison is not relevant.

Reply 2: As you pointed out, we deleted the results of comparisons between children and adults with the corresponding p-values throughout the manuscript. We reconstructed the results; that is, we described the results separately between children and adults.

Thank you.

Comment 3. All figures in the discussion section are confusing. In the results section,

figures describing children and adults are held apart whereas they are merged in the discussion. New figures should only be presented in the results section.

Reply 3: Thank you.

As you recommended, we reconstructed the results and discussion sections. We described them separately between children and adults.

Comment 4. In the abstract and in the results section, please specify how many patients who had cough-assist and chest-wall oscillation devices.

Reply 4: As you pointed out, we specified how many patients had an oxygen monitoring device and cough-assist in the Abstract. We deleted the chest-wall oscillator in the sentence.

Thank you.

Comment 5. In the results section when describing the age of the patients, is it range or interquartile range described?

Reply 7: It is interquartile range (IQR), not range. We corrected it.

We are sorry for that.

Comment 6. Reference 17 has been published and is no more “Online ahead of print”.

Reply 6: Although we downloaded and read the full-text, we couldn't find the volum

e and page numbers in the article (even in the Pubmed). But, we described details for the reference (reference No. 12 in the revised manuscript), instead of “Online ahead of print”.

Thank you.

Comment 7. One aim was to examine the “Out-of-pocket” expenses. The results are presented in table 4. The monthly sums of 50.0 and 100.0 \$ sound suspiciously much like round and nice figures.

Reply 7: We calculated the out-of-pocket expenses using the current Korean won-dollar exchange rate, and presented them again in the Table 4 and 5.

Comment 8. In the discussion section, why do the authors find it interesting to compare how many patients with LTMV who lives in the capital area?

Reply 8: The fact that our study was conducted only in three university-affiliated hospitals is one of the limitations. For your question, we couldn’t figure out an appropriate answer. However, we deleted the sentence, and redescribed the point in the 1<sup>st</sup> paragraph in the discussion section.

Comment 9. The authors discuss prevalence of HMV among children in South Korea – this has not been studied.

Reply 9: In fact, the prevalence of HMV use among children in South Korea was reported in several studies (Kim et al, Respir Care 2019; 64: 528-35 and Park et al. J

Korean Med Sci 2019; 34: e268-77). But, as you pointed out, we did not investigate the prevalence in the current study.

Hence, we deleted the sentences from the discussion. Thank you.

## **Reviewer B**

Comment 1. The method which is used raises several serious questions regarding the reliability and generalizability of the data.

Reply 1: Dear reviewer, we acknowledge what you concern about the method that was used in our study. We described how we obtained data in detail in the method section. And, we mentioned the problem of reliance and generalizerbility in the limitation of the discussion section.

Comment 2. Only 64 patients could be enrolled from three academic centers.

Reply 2: As described in the discussion section, most of subjects receiving HMV are not hospitalized for long-term care in university-affiliated hospitals in South Korea. Although they freuqently initiate HMV in university hospitals, most of them are transferred to community (or nursing) hospitals or nursing homes; for those patients, it was difficult to obtain written consent. Furthermore, among those receiving HMV at home, due to the COVID-19 pandemic, quite a few subjects with HMV or their families refused door-to-door visits (i.e., 28.9% [26/90 subjects]). We discribed this in the limitations in the discussion section (i.e., line 281-285) and hope that you understand this.

Thank you.

Comment 3. A high number of patients (>25%) did not give informed consent for an observational study.

Reply 3: As we answered the above comments, due to the COVID-19 pandemic, many subjects with HMV (or their families) refused door-to-door visits. We describe this as one of the limitations of our study in the discussion section.

Thank you.

Comment 4. Only patients living at home were included, a comparison with patients living in institutions should be valuable to compare safety, emergency problems etc and in case of major differences (worse outcome for patients living at home) should underline the statement of the authors that the care could be improved.

Reply 4: We totally agree with you. However, unfortunately, as explained above, we have very few patients receiving HMV in hospitals (i.e., university-affiliated hospitals).

After the initiation of HMV, many patients are frequently transferred to step down hospitals or nursing homes in South Korea. Because of it, we could not obtain the data from those patients. We hope that you understand this.

Comment 5. Regarding safety an important outcome should be the frequency of people who passed away.

Reply 5: As you pointed out, we investigated the mortality of the enrolled patients during the additional 8-month period after the initial investigation. The results are presented in the revised version. And, we also presented some details about those who died (n = 9) in a new Table (i.e., Supplementary Table S3).

Thank you.

Comment 6. From the methods section it becomes not clear how data were obtained. Only by patient administered questionnaires or also by checking data from medical record by the investigator or by read outs of medical device. The latter options should be the most accurate.

Reply 6: Thank you. We think that's an important point.

Most of data for home care support were collected during the interview using the questionnaire. However, regarding ventilator parameters, we directly extracted data from the ventilator machine when we visited them. And for clinical data including the primary diagnosis for HMV, we obtained them from the medical records.

In conclusion, I have serious worries about the methods (small group size, observational single-arm study, important outcome parameter of death is lacking, obtaining data only by questionnaire).

Reply : Thank you for your precise comments.

We understand what you are concerned about and agree with your opinion. With regard to the data collection, we answered in the above comments. And, we added the mortality rate in the main text and also newly presented whether the cause of death was disease progression or not in the Supplementary Table S3. Lastly, we mentioned them as limitations of our study in the end of the discussion section.

Thank you again.

Sincerely yours.

## **Reviewer C**

The authors present a very interesting multicentric cross-sectional study, which assesses home care support and health care resources utilization among patients on HMV. They analyze the data dividing in two main groups: adults and children and conclude that the challenges are huge for patients and families. This mostly descriptive data is relevant since it illustrates the need of health care systems to improve their support to these patients.

However some comments must be addressed before its final publication:

Comment 1. Lines 80-82: improve the english: do not repeat “were also investigated”

Reply 1: As you pointed out, we revised the sentences and did not repeat the phrase.

We have the revised manuscript edited again by a professional English editor.

Comment 2. Line 110 and Table 1: Lung and airway disease should be separated as they represent totally different types of diseases and have specific ventilatory strategies.

Reply 2: We agree with you.

As you pointed out, we separated lung and airway disease. We categorized the primary diagnosis for HMV use again and presented them in Table 1 and Supplementary Table 1.



Comment 3. The authors only present groups of diseases leading to HMV. They should had add a supplementary table with disease discrimination within each category (for example, airway disease – COPD? Bronchiectasis?)

Reply 3: As you recommended, we created a new supplementary Table (Supplementary Table S1) to present details for the primary diagnosis for HMV use.

Comment 4. In Table 2: EPAP value adults 5.0 (5.0 - 6.0) vs children 5.0 (5.0 -5.0). Is this p value (0.007) right?

Reply 4: We conducted the statistical analysis again and found that p value was not wrong. However, other reviewers recommended that we deleted all the comparisons between children and adults. So, we removed all the p values for the comparisons from the Tables. I hope you understand this.

Comment 5. In Table 4: The authors presented Regular visit by a nurse and by a provider per month. Better to analyze per year since the numbers are very low.

Reply 5: Thank you.

We presented it as “per year” instead of “per month”

## **Discussion**

Comment 6. In general, should become more critical about the results.

Reply 6: Thank you for your comments.

As you recommended, we reconstructed the discussion section, with focus on the results and limitations; we deleted some parts which were unrelated with the results in the discussion section

Comment 7. 1st paragraph should be improved. The authors should state clearly which was the main goal of the study and how this become important.

Reply 7: We revised the 1<sup>st</sup> and 2<sup>nd</sup> paragraphs in the discussion section. As you said, we described the main goals of the study. If there are anything to be corrected or added, please just tell us. Thank you.

Comment 8. Lines 166-169 – improve English

Reply 8: We have the revised manuscript edited again for English writing by a professional English editor. Thank you.

Comment 9. Line 170 “with a previous report” – reference?

Reply 9: We are sorry for this. It indicated an article, titled “Home Mechanical Ventilation Use in South Korea Based on National Health Insurance Service Data” (Respir Care 2019; 64: 528-35). We revised the sentence and cited the reference in the revised manuscript.

Thank you.

Comment 10. Lines 171-172 Starting “The S/T mode (67.2%)...” The authors repeat the results and do not explain or point a cause.

Reply 10: We understand what you mean. Although we could not find any clear reasons, we thought that pressure-targeted mode (including S/T mode) is the most commonly used mode, similar to that reported in other country (Daniel et al. Home mechanical ventilation in Australia and New Zealand. *Eur Respir J* 2013;41:39–45), and single-limb circuit with a leak valve is the most commonly used circuit configuration at home due to its simplicity (Park et al. Home mechanical ventilation: back to basics. *Acute Crit Care*. 2020;35:131-141). However, we deleted the sentence and added a new sentence in the discussion (line 232-233) as below.

“Except for that, neither the ventilator mode nor circuit configuration of the H MVs were remarkable (Table 2).”

Comment 11. 200 ALS – state what it means

Reply 11: We presented full names for all abbreviations when it appeared first in the manuscript, including ALS (“amyotrophic lateral sclerosis”). Thank you.

Thank you again.

Sincerely yours.

## **Reviewer D**

The authors report the results of a cross sectional study focused on characteristics of home mechanical ventilation in South Korea. I support the publication as the subject is relevant since there is little information on characteristics of care in this region, however the quality of the manuscript is not fit for publication at this time. I advise a major revision before re-evaluation.

Reply : Thank you very much for the careful review of our manuscript.

We did our best to revise the manuscript according to your comments.

### **Major concerns:**

Comment 1. The manuscript requires extensive English language editing as there are several grammatical and stylistic mistakes.

Reply 1: We are sorry for that. We have the revised manuscript edited again for English language by a professional English editor. Thank you,

Comment 2. The discussion part would benefit from a complete rewrite in order to make it more concise and to the point. Currently, it includes a lot of facts already stated in the Results section with limited analysis of what that data could mean and some conclusions that are not necessarily supported by the results presented.

Reply 2: Thank you for your comments.

As you recommended, we revised a lot of parts and reconstructed the discussion section. We rewrote the discussion with focus on the results and limitations, while avoidin

g redundancy. And, we deleted descriptions unrelated with our results in the discussion.

**Specific suggestions:**

Comment 3. Title: Consider altering the title, as “major problems” does not sound scientific. Perhaps “deficiencies”?

Reply 3: Thank you. As you recommended, we changed the title as follows

“Cross-sectional survey on home mechanical ventilator use: Major deficiencies in a home care system in South Korea”

Comment 4. The abstract does not include an objective, please include the ones stated in the Introduction part.

Reply 4: As you recommended, we added a sentence indicating the objective of our study in the Abstract.

Comment 5. The introduction part is a little confusing. I don't understand the sentence “However, the home care system pattern is thought to differ among countries”. Are you saying that both the prevalence and quality of care provided differs in European countries? This would be true, but please cite relevant literature to prove this point, other than the Eurovent study which mostly focused on prevalence. Additionally, the South Korean prevalence of 9.3 per 100,000 people is remarkably good, but it is unclear exactly what type of patients are included in this number. Does this also include

long term hospital ventilated patients? Patients receiving only CPAP treatments?

Reply 5: Thank you for your comments,

For the sentence you mentioned, we cited some references, other than the Eurovent study.

The prevalence of 9.3 per 100,000 people in South Korea was from the National Health Insurance Service (NHIS) data. Hence, as well as subjects receiving HMV at home, patients receiving HMV (i.e., using a portable MV in a form of long-term mechanical ventilation) in community hospitals or nursing home were also included. We newly described this point in the introduction section as follows.

“The estimated rate of HMV use in a European survey was 6.6 per 100,000 people, with the highest rate reported in France (17/100,000 people) (1). In South Korea, the NHIS has estimated a prevalence of 9.3 per 100,000 people, where hospitalized patients for long-term care were included (8). However, both the prevalence and quality of HMV-based care are likely to differ among countries (9-14).”

Comment 6. In the Methods section, it is not clear what the 3 centers did and how patient selection worked. The study patients were recruited from all patients initiated by these 3 centers?

Reply 6: Yes, as you said, all enrolled subjects initiated their HMV in the three hospitals participating in the current study. We added sentences for this in the method section

Thank you

Comment 7. It is also unclear how home mechanical ventilation is defined, as it seems from the flowchart that patients on long-term ventilation treated in a hospital setting were also included in the 140 patients. Furthermore, you state that obstructive sleep apnea patients (usually treated with CPAP) were excluded suggesting that your definition of ventilation entails bi-level respiratory support, but then Table 2 includes CPAP in 'Modes'.

Reply 7: We are sorry for the confusion.

1) Firstly, in South Korea, there are many patients who are receiving HMV (i.e., a portable home ventilator) in community (or nursing) hospitals or nursing homes: these patients are usually those who were transferred from university-affiliated hospitals after HMV initiation.

2) As you pointed out, in the 1<sup>st</sup> paragraph of the method section, we clarified the subjects who were receiving HMV at home and enrolled in our study as follows.

“All patients who had initiated HMV in the three hospitals were screened, but only those who were discharged and had been using HMV at home for > 3 months were included. Patients using an HMV machine in the hospital or nursing home, and those with obstructive sleep apnea (OSA), were excluded.”

And, we revised the Figure 1 (flowchart) slightly.

3) Regarding the four subjects (children) receiving CPAP mode, we found that two of

them received S/T mode, not CPAP. However, the remaining two children received CPAP mode via a nasal mask. But, they did not have OSA. Unfortunately, we could not find the reason. We described this point in the discussion section.

We hope you understand this.

Comment 8. The indications for HMV are not the terms traditionally used in HMV literature. Does lung/airway refer to COPD? This might need to be elaborated. On the other hand, several neurological conditions are listed, but it seems like these cases might have been weaning failures and not cases initiated on home mechanical ventilation electively.

Reply 8: Thank you for your comments.

As you pointed out, we classified the primary diagnosis again and reconstructed Table 1. We also added a new supplementary table (Supplementary Table S1) to present details for primary diagnosis for HMV use.

And, about the possibility of the initiation of HMV due to weaning failure for those with neurological conditions, we agree with you. However, in fact, we could not confirm whether the subjects-initiated HMV electively or after weaning failure. Instead, we added this point as a limitation in the end of the discussion section.

Thank you.

Comment 9. You use the term life support ventilator, but this is not defined. Is this 24-hour ventilation? Or ventilation using controlled modes?



Reply 9: Although there is not clear definition for a life-support ventilator now, as you recommended, we described the definition for life-support ventilator in the method section, with references, as follows.

“In this study, life support ventilators were defined as ventilators with both volume and pressure modes as well as advanced monitoring systems, and considered appropriate for highly ventilator-dependent patients (6,8).”

Comment 10. Page 7, line 139: It is unclear what n=11 refers to. You are talking about specialized nurse visits, but Table 4 suggests none of the patients had access to this.

Reply 10: We are sorry for the confusion.

It was because the frequency of the monthly visits (per subject) by a hospital nurse was too low. Hence, we revised this. We presented it as the number of subjects who had any home visit services by a hospital nurse during the previous year (10 [26.3%] in adults and 1 [3.8%] in children) in Table 4.

Comment 11. ‘Emergency incident’ needs to be defined in Methods. Are these referring to cause for readmission? This is unclear since emergency incidents range from ventilator alarm (quite common in HMV patients) to syncope (obviously cause for readmission).

Reply 11: Thank you for your comments.

We defined the emergency incidents in the method section as follows.

“; the occurrence of emergencies (safety incidents), defined as emergency calls to a helpline or emergency department visits; ”.

And, in the discussion section, we described that the emergency incidents were defined arbitrarily in our study. We also reconstructed the supplementary table for the emergency incidents in the revised manuscript (Supplementary Table S2): we presented the type of events and its numbers among 28 patients in the table.

Comment 12. ‘HMV provider’ and ‘specialized nurse visit’ also need to be defined in Methods, as these definitions aren’t straight forward. HMV provider is a company providing equipment but no medical supervision? And by specialized nurse visits do you mean continuous care or check-ups? Does that mean that HMV patients don’t have regular at-home or outpatient appointments provided by the 3 centers?

Reply 12: In this study, HMV providers indicate equipment (company) providers who usually check-up ventilator machines only. Regarding the specialized nurse, we changed the term as the “hospital nurse” because there is no specialized nursing qualification systems for HMV in South Korea. We rewrite the sentence again in the “Data Collection” in the method as follows.

“home visit services for ventilator check-ups by a HMV equipment provider and home care services delivered by a hospital (registered) nurse;”

In South Korea, subjects with HMV or their family members visit outpatient department

nts or have home care services delivered by a hospital nurse. However, it is likely that they are made irregularly or intermittently. In particular, we think that home care services delivered by hospital nurses are taking place less frequently. It is because there is no obligations or regulations for home nursing service (by hospital nurses) in our country. This is one of the reasons why we conducted this study.

We hope you understand this situation.

Thank you.

As mentioned, the Discussion part would benefit from a complete rewrite. It seems to me that the point you were trying to make is that despite relatively high prevalence of HNV in South Korea, standard of care is not well defined for these patients (no national guideline?), so you conducted a study to evaluate current practices and potential deficiencies in care provision.

Reply:

Thank you for your comments.

As you recommended, we inserted the sentences in the 1<sup>st</sup> paragraph in the discussion section. And, as abovementioned, we rewrote and reconstructed the discussion in the revised manuscript.

For this to be objective, I suggest reviewing currently available international HNV guidelines (German, Canadian) that focus on aspects studied in this study (e.g. what type of ancillary devices are indicated in what situations, what monitoring, follow-up, an

d level of care is required for HMV patients) and comparing your findings to those requirements.

Reply: We think you made the important point.

Although we couldn't add many contents in the manuscript due to the limitation of space, as you recommended, we mentioned the German and Canadian guidelines about the ancillary devices and several requirements for HMV use at home in the discussion and added them in the references.

**The present Discussion is not cohesive and includes several problematic points, such as:**

Comment 13. Suction devices are indicated for patients with tracheostomies. Cough assist devices are indicated if peak cough flow is below 250L/min. It is unreasonable to expect all patients to be equipped with these devices if they are not indicated in their condition (for example in a patient on NIV with sufficient cough flow). It's unclear whether your data reflects a deficiency in care or just shows that these devices were not indicated for all patients.

Reply 13: Thank you for your comments.

As you recommended, we cited the German Guidelines, and described that cough assist devices are required for subjects whose peak cough flow is less than 270 L/min. And, we also described that AMBU-bag and suction devices are usually required for tracheostomy ventilated subjects. We rewrote the sentences to show a deficiency in home care system.

Comment 14. Pediatric indications for HMV are generally more complex than adult ones and more often require invasive form of ventilation (tracheostomy), so comparison of adult and pediatric groups in this regard is pointless.

Reply 14: We totally agree with you.

So, we described the results and discussion separately between children and adults in the revised manuscript.

Comment 15. Lines 209-221 discuss issues that were not the subject of this study (no questions were focused on caregiver training or emergency protocols), hence I would omit this part.

Reply 15: Thank you for your comments.

We deleted the sentences about caregiver training and emergency protocols.

Comment 16. Similarly, lines 222-227 discuss monitoring and malfunction review, which were not addressed in the present study, so no conclusions on these subjects should be made in this study.

Reply 16: Thank you for your comments.

We agree with you. We deleted the discussion on monitoring and malfunction.

Comment 17. The conclusion paragraph is not clear.

Reply 17: We rewrote the conclusion paragraph to clarify our results and claims (opinions),

Thank you again for the careful review and valuable comments.

Sincerely yours.

## **Reviewer E**

Comment 1. The authors must say which proportion of the country is represented by those clinics where the survey was done.

Reply 1: Dear reviewer,

In fact, it is difficult to say which proportion of the country is represented by the three hospitals participating in this study. The three hospitals were university-affiliated hospitals, located in Seoul metropolitan area, and it is just that we could recruit patients only from the three hospitals than we initially planned. We described this in the limitation in the discussion section. We hope you understand this.

Also, we described this point in the 1<sup>st</sup> paragraph in the discussion section as follows.

“Although our study was limited to several parts of the Seoul metropolitan area, the findings in other areas of South Korea are likely to be similar, because most of the patients in our cohort lived in urban areas where the healthcare system and infrastructure are relatively well established.”

Comment 2. And they cannot mix the information given by the patients with the one that was collected by clinicians. This comment relates to diagnosis, where there is a big confusion. COPD is a major diagnosis referred to about more patients than lung/airways disease.

Reply 2: Thank you.

As you pointed out, we categorized the primary diagnosis again in Table 1 and added a new supplementary table (Supplementary Table S1) to represent the details in the

primary diagnosis.