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Original Article

Long-term Home Mechanical Ventilation of Children in İstanbul

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Abstract

OBJECTIVE: The aims of this multi-center study were to describe the characteristics of children receiving long-term home mechanical ventilation (HMV) in İstanbul and to compare the patients receiving non-invasive and invasive ventilation.

MATERIAL AND METHODS: This cross-sectional multicenter study included all children receiving long-term HMV followed by admission to six tertiary hospitals. The data were collected between May 2020 and May 2021. Demographic data and data regarding HMV were collected from the patient charts.

RESULTS: The study included 416 participants. The most common diagnoses were neuromuscular (35.1%) and neurological diseases (25.7%). Among the patients, 49.5% (n = 206) received non-invasive ventilation (NIV), whereas 50.5% (n = 210) received invasive ventilation. The median age at initiation was significantly younger in the invasive ventilation group than in the NIV group (10 vs. 41 months, $P < 0.001$). Most subjects in the NIV group (81.1%) received ventilation support only during sleep, whereas most subjects in the invasive ventilation group (55.7%) received continuous ventilator support ($P < 0.001$). In addition to ventilation support, 41.9% of the subjects in the invasive ventilation group and 28.6% in the NIV group received oxygen supplementation ($P = 0.002$). Within the last year, 59.1% (n = 246) of the subjects were hospitalized. The risk factors for hospitalization were invasive ventilation, continuous ventilatory support, oxygen supplementation, tube feeding, and swallowing dysfunction ($P = 0.002$, 0.009, <0.001, <0.001 and <0.001 respectively).

CONCLUSION: Despite the increasing use of NIV in most studies, half of the study population received invasive ventilation. Patients receiving invasive ventilation were more likely to require continuous ventilator support and oxygen supplementation and were at increased risk of hospitalization.

KEYWORDS: Non-invasive ventilation, neuromuscular disorders, long-term home mechanical ventilation, chronic respiratory failure

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INTRODUCTION

Advances in technology have increased the long-term survival rate of patients with chronic respiratory failure. Thus, the number of patients receiving long-term home mechanical ventilation (HMV) support is increasing worldwide. The number of children requiring HMV has consistently increased in high-income countries since the 1980s.[1-4] Currently, there is no national database for long-term HMV patients in Türkiye, and the prevalence of children requiring HMV is not well known. In recent decades, an increasing number of children have started long-term non-invasive ventilation (NIV) rather than invasive ventilation to improve survival rates and quality of life while avoiding complications related to tracheostomy. However, invasive ventilation via tracheostomy is still needed in selected cases.[5]

Successful care of this vulnerable population at home requires the presence of trained caregivers, access to medical equipment, and a care team. Full-time ventilatory support, supplemental oxygen requirement, and inadequate home nursing are frequent reasons for hospital re-admissions.[6]

The aims of this multi-center study were to describe the characteristics of children on long-term HMV in İstanbul, to compare patients receiving NIV and invasive ventilation, and to evaluate the frequency and risk factors of hospital admission in this population.

MATERIAL AND METHODS

Study Design and Participated Centers

We conducted a multicenter, cross-sectional study that included patients with long-term HMV followed by pediatric pulmonology divisions at six tertiary hospitals in İstanbul. The study was approved by the İstanbul Medipol University Ethics Committee (protocol number: 586, date: 06.08.2020). The ethics board waived the need for consent.

Data Collection

All children on long-term HMV follow-up at these six centers were included in the study. The data were collected between May 2020 and May 2021. Long-term HMV was defined as the requirement of mechanical support for breathing for all or part of the 24-hour day and living for at least three months outside the hospital or non-acute care settings.[7,8] Children on HMV for three months and those with tracheostomy but without ventilator support were excluded. Demographic characteristics, underlying diseases, comorbidities, characteristics of ventilation, duration between the decision to initiate and actual start of HMV, duration of HMV, and duration of ventilation use per day (during sleep versus continuous ventilatory support, ≥16 hours of HMV), feeding method, presence of swallowing dysfunction, and nutritional status at the time of the study were recorded. For patients receiving HMV for more than 12 months, data regarding hospitalizations during the last 12 months related to respiratory complications were obtained from medical records. Primary diagnoses for HMV were neuromuscular disorder (NMD), neurological disease (anoxic, hypoxic, or traumatic brain injury), congenital central hypoventilation syndrome, lung parenchymal disease, airway anomalies, congenital heart disease, genetic/syndromic/metabolic disease, and thoracic deformities. Indications for HMV were categorized as follows: acute exacerbation of underlying chronic disease, obstructive sleep apnea syndrome (OSAS), central or mixed apnea diagnosed by polysomnography (PSG); hypoxemia, hypoxemia and hypercapnia, persistent atelectasis, and increased work of breathing. The PSG criteria were as follows: moderate OSAS (obstructive apnea-hypopnea index >5 events/hr), central apnea with hypoventilation (central apnea index >5 events/hr), and isolated hypoxemia (SpO_2 <90% for >5 minutes).[9] Hypercapnia was defined as pCO_2 >45 mmHg in the venous blood gas analysis.[10] Education provided to caregivers of invasively ventilated subjects (bag-valve-mask ventilation, suctioning, tracheostomy care training, and as well as tracheostomy tube changing), equipment at home (suction, oxygen cylinder and concentrator, nebulizer, bag-valve-mask, pulse oximeter, power supply, humidifier, feeding pump), and availability of technical support for both groups were also recorded.

Main Points

- The use of invasive ventilation is higher in low-compared with high-resource countries.
- In this study, we revealed the challenges associated with initiating and sustaining a home mechanical ventilation program in a low-resource country.
- In addition, invasive ventilation, tube feeding, swallowing dysfunction, and malnutrition were risk factors for hospital re-admission.

Statistical Analysis

The IBM Statistical Package for the Social Sciences statistics (version 22.0 IBM Corp., Armonk, NY) software was used to analyze the data. Categorical variables are presented as numbers (n) and percentages (%). Continuous variables are reported as medians with interquartile range (IQR) because the data did not follow a normal distribution. Categorical variables were compared using Pearson's chi-square test and Fisher's exact test. Continuous variables for the two groups were compared using the Mann-Whitney U test. A P value <0.05 was considered significant.

RESULTS

Demographic Characteristics

A total of 416 patients from six pediatric pulmonology centers in İstanbul were included in the study. The median age of the children was 4.3 years (IQR: 2.0-10.3 years), and 54.1% were male. The demographic characteristics of the participants are presented in Table 1. According to weight and age z-scores, 132 (55%) subjects were malnourished. One hundred and sixty five (39.7%) children were fed orally, 96 (23.1%) were fed via nasogastric/nasoduodenal tube, 129 (31%) were fed via gastrostomy tube, and 8 (1.9%) were fed via more than one feeding route. Swallowing dysfunction was detected in 198 (47.6%) participants. While 30.8% (n = 60) of the NIV group had swallowing dysfunction, 72.3% (n = 138) of the invasive ventilation group had swallowing dysfunction (P < 0.001). In addition, a significantly greater proportion of subjects

receiving continuous ventilator support had swallowing dysfunction compared with subjects receiving ventilation support only during sleep (71.9% and 37.6% respectively, *P* < 0.001). Factors affecting malnutrition were identified. There were no statistically significant differences in the following variables: type of ventilation, age at initiation of HMV, duration between HMV decision and start of HMV, duration of HMV, oxygen supplement, presence of swallowing dysfunction, and presence of immobility. There was only a statistically significant difference in the presence of gastroesophageal reflux disease (49.3% vs. 34.4%, p = 0.008).

Characteristics of Ventilation Support

In the current study, 49.5% (n = 206) of children received NIV and 50.5% (n = 210) received invasive ventilation. The demographic data of the participants according to the type of ventilation are presented in Table 1. The median age at tracheostomy placement was 8.6 months (IQR: 4.5-30.7 months). In three centers, covering 56.3% (n = 234) of the study group, the NIV rate was 61.1% (n = 143). In the remaining three centers, the NIV rate was 34.6% (n = 63). In centers with a low NIV rate, both the number of children with NMD or neurological disease (70.3% vs. 53.4%, *P* < 0.001) and the number of children <2 years of age were significantly higher (30.2% vs. 20.9, p = 0.03). Among the children receiving NIV support, 61 (29.8%) received bilevel positive airway pressure-spontaneous (BPAP S) support and 137 (66.8%) received BPAP-spontaneous/timed (BPAP S/T) support. Nasal mask was used in 61.4% (n = 113), oro-nasal in 36.4% (n = 67), and full face masks in 2.2% (n = 4) of children. Thirty (15.2%) patients who received NIV and 117 (55.7%) patients who received invasive ventilation were on continuous ventilator support.

The Starting Location and Indications for Long-term HMV

HMV was initiated in the intensive care unit (ICU) following acute exacerbation of underlying chronic lung disease in 208 (50%) subjects and in the ward in 208 (50%) subjects. In cases where HMV was initiated in the ward, the decision to start was based on the PSG in 26.9% (n = 56) of the children and on blood gas and clinical status in 73.1% (n = 152). The starting location and indications for HMV, including NIV and invasive ventilation, are presented in Figure 1.

Primary Diagnosis for HMV

NMDs were the most common primary diagnosis, and 146 (35.1%) subjects had NMD. Most children with NMD (n = 102) had type 1 spinal muscular atrophy (SMA). Ninety-six percent of patients with SMA type 1 and type 2 were on nusinersen treatment, and none were on olgensis, which is not covered by health insurance in Türkiye. The distribution of underlying disorders in the NIV and invasive ventilation groups is presented in Table 2.

Hospital Re-admissions

Fifty-nine percent of the subjects were re-hospitalized within the last 12 months. Risk factors for hospitalization are presented in Table 3. Invasive ventilation, continuous ventilatory support, oxygen supplementation, tube feeding, the presence of swallowing dysfunction, and malnutrition according to weight for age z-scores were significantly higher in hospitalized patients (*P* values 0.002, 0.009, <0.001, <0.001, <0.001 and 0.03 respectively). In the multivariate logistic regression analysis, oxygen support [odds ratio (OR): 3,125; 95% confidence interval (CI): 1.8-5.3, *P* < 0.001] and tube/PEG feeding (OR: 3,928; 95% CI: 1.9-7.9, *P* < 0.001) were found to be significant risk factors for re-hospitalization.

Table 1. Demographic data of patients according to ventilation type

	NIV (n = 206) Median (interquartile range)	Invasive ventilation (n = 210) Median (interquartile range)	Total (n = 416) Median (interquartile range)	*P*
Age, years,	6.5 (2.3-13)	3.9 (2-7.4)	4.3 (2-10.3)	**<0.001**
Sex n (%)				
Male	112 (54.4)	113 (53.8)	225 (54.1)	0.90
Female	94 (45.6)	97 (46.2)	191 (45.9)	
Nutritional status				
WAZ	-1.3 [-2.9-(-0.1)]	-0.9 (-2.0-0.4)	-1.2 (-2.7-0.1)	0.06
HAZ	-1.5 [-3.1-(-0.6)]	-1.4 [-2.5-(-0.2)]	-1.5 [-2.9-(-0.3)]	0.23
BMI z-score	-0.5 (-2.3-0.8)	0.2 (-1.8-1.5)	-0.3 (-2.0-1.1)	0.17
Ventilation data				
Age at HMV initiation (months)	41 (11-123)	10 (5-43)	18 (7-83)	**<0.001**
Duration between HMV decision and HMV start	8 (2-16)	30 (15-45)	15 (5-30)	**<0.001**
Duration of HMV, months	14 (6-32)	17 (6-37)	16 (6-36)	0.21
HMV during sleep n (%)	167 (81.1)	71 (33.8)	238 (57.2)	**<0.001**
Continuous ventilator support n (%)	30 (14.6)	117 (55.7)	147 (35.3)	**<0.001**
Number of patients receiving oxygen n (%)	59 (28.6)	88 (41.9)	147 (35.3)	**0.002**

NIV: non-invasive ventilation, WAZ: weight for age z-score, HAZ: height for age z-score, BMI: body mass index, HMV: home mechanical ventilation

Characteristics of Home Care and Education

The primary caregivers of the subjects were mothers in 93.9% (n = 371), fathers in 1.8% (n = 7), other family members in 1% (n = 4), nurses in 0.8% (n = 3), and more than one person in 2.5% (n = 10). Only 1.9% of the NIV group and 6.2% of the invasive ventilation group used a back-up ventilator.

According to parental reports, 86.6% of the caregivers received suction training, 80.5% received tracheostomy care training, 87.1% received bag-valve-mask ventilation training, and 65.7% received tracheostomy tube change training in the invasive ventilation group. However, only 37.1% of the patients changed the tracheostomy tube before discharge. A spare tracheostomy tube was available in 80.5% of children, while a smaller tube was available in only 59.5% of children. Thirty-eight percent (n = 80) of families used the sterile technique, 28.1% (n = 59) used the clean technique, and 23.3% (n = 49) used the modified sterile technique for tracheostomy tube change. While 60.9%

Table 2. Distribution of underlying disorders in the NIV and invasive ventilation groups

	Non-invasive (n, %)	Invasiveness (n, %)
NMD (n = 146)	71 (34.5)	75 (35.7)
Neurological diseases (n = 107)	36 (17.5)	71 (33.8)
Lung parenchymal diseases (n = 60)	48 (23.3)	12 (5.7)
Airway anomalies, sleep apnea (n = 13)	10 (4.9)	3 (1.4)
Congenital heart diseases (n = 13)	6 (2.9)	7 (3.3)
Genetic, syndromic, and metabolic diseases (n = 67)	29 (14.1)	38 (18.1)
Congenital central hypoventilation syndrome (n = 7)	4 (1.9)	3 (1.4)
Thorax deformities (n = 3)	2 (1.0)	1 (0.5)

NMD: neuromuscular disorder, NIV: non-invasive ventilation

Table 3. Comparison of children who required hospitalization within the last year with children who did not require hospitalization

		Hospitalization		
		No (n = 132) n (%)	Yes (n = 246) n (%)	*P* value
Ventilation mode	NIV	82 (42.5)	111 (57.5)	**0.002**
	Invasive ventilation	50 (27)	135 (73)	
Need for ventilation	On sleep	93 (40.3)	138 (59.7)	**0.009**
	Continuous	36 (26.7)	99 (73.3)	
Presence of oxygen supplementation		29 (20.0)	116 (80.0)	**<0.001**
Feeding method	Oral	85 (52.8)	76 (47.2)	**<0.001**
	Tube feeding/ gastrectomy	47 (21.7)	170 (78.3)	
Presence of swallowing dysfunction		46 (24.3)	143 (75.7)	**<0.001**
Malnutrition according to the WAZ		44 (33.3)	88 (66.7)	**0.03**

NIV: non-invasive ventilator, WAZ: weight for age z-score

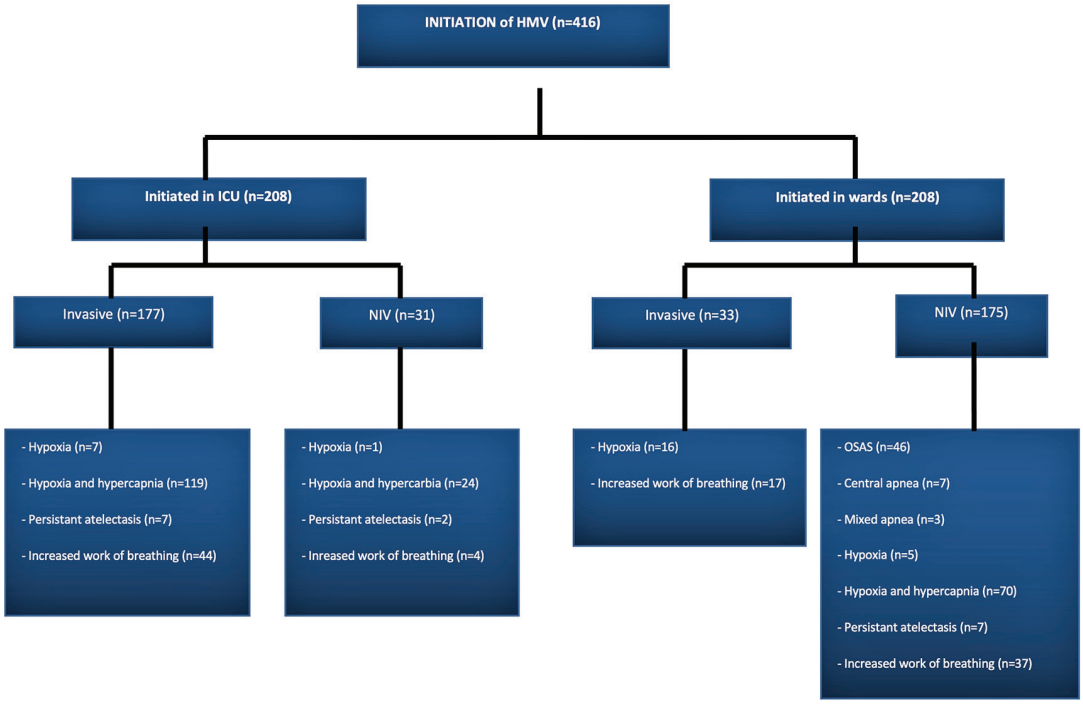

Figure 1. The starting location and indications for long-term HMV

HMV: home mechanical ventilation, ICU: intensive care unit, NIV: non-invasive ventilator, OSAS: obstructive sleep apnea syndrome

(n = 128) of the subjects were suctioned at a depth of 0.5-1 cm past the cannula tip, 13.3% (n = 28) of the caregivers advanced the suction catheter until the carina, where resistance was met.

DISCUSSION

The current study showed that the number of children receiving invasive ventilation was higher than that receiving NIV, and invasive ventilation, tube feeding, swallowing dysfunction, malnutrition were the risk factors for hospital re-admissions. In contrast to other studies reporting invasive HMV rates of 13-49%, these rates remained high in İstanbul.[1-4,7] Advances in pediatric critical care and the availability of improved technology have resulted in prolonged life expectancy among patients on HMV.[5] HMV minimizes disruptions to family life, prevents nosocomial infections, decreases hospitalization, and lowers healthcare costs.[11] Tibballs et al.[12] reported that healthcare costs are seven times lower at home and 25 times lower in the ICU. Several studies have shown that well-organized referral hospitals from low- and middle-income countries can also implement adequate HMV programs.[5,13] NIV is a simpler method for assisted ventilation, which prevents tracheostomy-related complications, including acute airway blockage by secretions, accidental decannulation, tracheal injury, and respiratory infections, whereas invasive ventilation is a life-support ventilation method, requiring more skills and 24-hour caregiving at a higher cost.[14,15] Significant differences in the proportion of children receiving long-term invasive ventilation versus NIV at home have been reported between countries. The reported rates of invasive ventilation vary globally between 14% and 49%.[1,4] Another interesting finding was detected in the United Kingdom's report on the 10-year progress. The proportion of children who underwent 24-h tracheostomy ventilation decreased from 23.4% to 9.5%, and they attribute this to their increasing experience with NIV.[1] Our invasive ventilation rate might decrease in the future as a result of the knowledge this study has provided.

In this study, half of the subjects were placed on invasive ventilation. The median age of children who received invasive ventilation was significantly lower than that of children who received NIV (3.9 vs. 6.5 years). Invasive ventilation/NIV rates vary between the study centers due to differences in clinical management and the patients' underlying etiologies and ages. The NIV rate was 66% in the three centers that participated in the current study, including the 60% study group. The NIV rate was 34% at the other three centers. In centers with a low NIV rate, the number of children with NMD and neurological disease was significantly higher (70.3% and 53.4%, respectively), and the number of children <2 years of age was higher. Invasive ventilation is usually considered an effective first-line supportive care option for children with SMA type 1 and/or younger children, especially when continuous ventilator support is needed. The availability of PSG may be another contributing factor to decision-making. Centers with sleep laboratories may be more likely to initiate NIV in infants or young children, and surveillance PSGs can facilitate elective NIV initiation by detecting nocturnal hypoventilation and sleep problems. In our study, HMV was initiated after PSG in only 13.5% of the participants because pediatric sleep laboratories are not widely available in Türkiye. The proportion of patients who underwent sleep study before starting HMV differs between countries and centers. Although Kim et al.[17] reported that PSG was possible only in a limited number of patients (3.3%) in South Korea, Leske et al.[16] reported that 70% of patients had sleep studies before ventilation initiation in Argentina.

Although the percentage of primary indications for HMV use in children varies among countries, NMDs are frequently the most prevalent diagnosis, followed by encephalopathy and hypoxic brain damage. These variabilities may be influenced by many factors, such as cultural characteristics, healthcare systems, the extent of reimbursement programs, and access to HMV.[17] In our study, 55% of patients with long-term HMV had NMD or neurological disease. This result was consistent with other studies in the literature.[1-3]

Several studies have reported that malnutrition is associated with a poorer quality of life, worse pulmonary function, a higher risk of mortality, a higher risk of infections, and decreased physical conditioning in adults with chronic respiratory failure requiring HMV.[18-20] However, to our knowledge, only one study has evaluated the relationship between nutritional status and respiratory outcomes in children.[21] Although the assessment of feeding and nutrition is vital, there are no clinical practice guidelines for HMV in children that outline optimal nutritional management. A scoping review protocol on feeding and swallowing outcomes of children receiving long-term ventilation has just been published, and the findings of this research will fill in many of the knowledge gaps on this topic.[22] In this study, malnutrition was detected in 32% of subjects, and hospitalization rates were higher in subjects with malnutrition. Forty-seven percent of our subjects also had clinical findings suggestive of swallowing disorders, and the frequency of re-hospitalization in these children was also significantly higher. Feeding and swallowing difficulties may be caused by any medical condition, injury, developmental delay, decreased oral stimulation, medical instability at the beginning of long-term ventilation, and length of invasive ventilation.[23-25] In the analyses of factors affecting malnutrition in our study, only the presence of gastroesophageal reflux disease was detected significantly more frequently in children with malnutrition (49.3% vs. 34.4%), but we cannot claim that this is a reason for malnutrition. Timely evaluation of feeding and swallowing by a speech and language therapist is vital for these children, and necessary precautions should be taken to prevent complications such as aspiration pneumonia and atelectasis.

Children on HMV are vulnerable and frequently require re-admission.[6] Re-admissions often occur shortly after discharge due to inadequate training of families and community health providers. Patients and/or caregivers should be appropriately trained to know how to operate the equipment, identify problems, and seek assistance when needed. Although educational materials are widely available, a lack of educational programs was reported by 27% of respondents in an ERS survey.[26] Our study revealed that 80-90% of the caregivers received education on tracheostomy care and suctioning, basic life support, home ventilator, and equipment. However, only 37.1% of the patients stated that they had changed the tracheostomy tube before discharge. There is a need to implement standardized training programs for caregivers of children requiring invasive ventilation.

Based on these results, we started standard education programs for healthcare providers and caregivers of invasively ventilated children in centers participating in this study. The education program consisted of theoretical and practical sessions using a simulation model.[27,28] Pediatric pulmonologists who completed the program trained the caregivers.

This study has several limitations. The current study included patients who were seen for a pulmonology clinic follow-up visit within 1 year at the six study centers, and data were collected retrospectively. We assumed that all long-term HMV patients in İstanbul are followed at one of the study centers, although it is probable that a small number of patients are not followed by a pediatric pulmonologist and are not included in the study. Additionally, the rate of hospital re-admissions may have been low as a result of the isolation due to the coronavirus pandemic. Despite these limitations, our study is the first multicenter study to include a large number of patients with HMV in Türkiye.

CONCLUSION

Children on long-term HMV are a diverse group of patients with complex medical problems, including respiratory, nutritional, and swallowing difficulties, and multidisciplinary follow-up is important to improve quality of life and decrease morbidity and mortality. In our study, invasive ventilation was higher than that in other studies, and invasive ventilation, tube feeding, swallowing dysfunction, and malnutrition were found to be higher in hospitalized patients, and gastroesophageal reflux disease was detected more frequently in children with malnutrition. Although this study characterized several previously unknown trends regarding HMV use in our region, a national registry is necessary to reveal the status of HMV use in the country. A national registry of pediatric patients with long-term HMV was recently approved as a research project by the Turkish Thoracic Society. Data from the current study will aid in planning the national registry and ultimately the optimal healthcare system for patients with long-term HMV.

Ethics

Ethics Committee Approval: The study was approved by the İstanbul Medipol University Ethics Committee (protocol number: 586, date: 06.08.2020).

Informed Consent: The ethics board waived the need for consent. So the informed consent was not obtained.

Footnotes

Authorship Contributions

Concept: M.Y., A.P.E., E.A., N.B.I., A.A.K., E.E.E., Y.G., S.O., E.C., S.G., Z.S.U., H.C., B.K., F.K., Design: M.Y., A.P.E., E.A., N.B.I., A.A.K., E.E.E., Y.G., S.O., E.C., S.G., Z.S.U., H.C., B.K., F.K., Data Collection or Processing: M.Y., F.U., E.H., H.Y., S.C.O., E.K., C.Y.Y., A.K.B., Z.R.O., A.G., A.S., M.K., H.B.K., Y.A., S.U., Analysis or Interpretation: M.Y., P.A., E.E.E., Y.G., S.O., E.C., S.G., Z.S.U., H.C., R.E., B.K., F.K., Literature Search: M.Y., A.P.E., E.A., N.B.I., Writing: M.Y., F.U., E.H., F.K.

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