INTRODUCTION

In the past few decades, more children have received home mechanical ventilation (HMV); today, approximately 300 children in Sweden are receiving HMV. These children constitute a diverse group, regarding not only their diagnosis and breathing problems but also their complex healthcare needs, which results in medical fragility and functional limitations. Home mechanical ventilation can be delivered invasively via a tracheostomy tube or noninvasively (NIV) and for only part of the day, typically during sleep, or continuously for 24 hours a day. Although HMV supports respiratory function, it does not alleviate other conditions; thus, a wide variety of unique

Abbreviations: CPAP, continuous positive airway pressure; HRQoL, health-related quality of life; ISI, Insomnia Severity Index; NIV, noninvasive ventilation; PCA, personal care assistant; PedsQL, Paediatric Quality of Life.

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and complex care services are delivered in the homecare environment, outside of a hospital setting.\textsuperscript{1}

A consequence of the homecare setting is the parents’ extended medical responsibility. Health-related quality of life (HRQoL) and family functioning are affected among parents to children with HMV treatment.\textsuperscript{5,6} Families have in many ways taken the responsibility for required advanced homecare, which often involves high vigilance and administering skilled care both day and night.\textsuperscript{7} Parents to children with congenital central hypoventilation syndrome frequently experience a disturbed night sleep,\textsuperscript{8} and several aspects of a perceived HRQoL are affected in parents to children receiving HMV.\textsuperscript{9} Mothers, in particular, have reported poor sleep quality.\textsuperscript{10} Parents often go to bed in a state of readiness, prepared to respond to alarms from medical devices.\textsuperscript{9} Some parents wake up early in the morning to perform technical care and routines.\textsuperscript{7} Emotional and cognitive symptoms of stress related to poor sleep can pose a threat to a person’s well-being,\textsuperscript{11} their relationships and their capacity to maintain vigilance and good quality of care.\textsuperscript{12}

Caring for a child receiving HMV often changes and effects the parents’ role and functioning within the family\textsuperscript{13} as well as their ability to perform daily activities, handle family finances\textsuperscript{1} and care for the well-being of other family members.\textsuperscript{14} Research highlights that it is often the mother who has the main responsibility for the child’s care\textsuperscript{15} and, frequently, when it becomes impossible for both parents to keep up their employment it is often the mother who gives up her professional life and career.\textsuperscript{13} Swedish legislation supports parents to work as a personal care assistant (PCA) for their own child.\textsuperscript{16} If and how that in this context affects parents’ ability and wish to work outside home is unknown.

The complex needs of a child with HMV affect the parents’ HRQoL, functioning\textsuperscript{13} and sleep.\textsuperscript{9} The parental role often changes to include nursing dimensions,\textsuperscript{13} and parents may experience significant negative physical and emotional consequences to their own health.\textsuperscript{17} There is an inextricable link between parental HRQoL and the child’s well-being which make it vital to focus on parental HRQoL, family functioning and sleep from a family systems perspective.\textsuperscript{18} HMV mode and care situations have, to the best of our knowledge, not been explored in relation to parents’ HRQoL, family functioning or sleep in a Swedish context. The aim of the study was therefore to explore HRQoL, family functioning and sleep in parents of children receiving HMV in Sweden. A secondary aim was to explore the impact on HRQoL, family functioning and sleep of selected potential determinants.

2 | PATIENTS AND METHODS

2.1 | Design

A cross-sectional study was designed using parent-reported data for exploring parents’ HRQoL, family functioning and sleep in relation to being a mother or father. The child’s HMV mode was defined as (a) tracheotomy, (b) noninvasive ventilation (NIV) or (c) continuous positive airway pressure (CPAP). Home mechanical ventilation mode and if the parents were employed as a PCA or in paid work outside home were related to the PedsQL Family Impact Module and Insomnia Severity Index (ISI) reports.

Key notes

- The population of children with home mechanical ventilation (HMV) have grown, and parents are in many ways responsible for the advanced homecare.
- No differences between mothers and fathers overall HRQoL and family functioning reports were found.
- Parent’s sleep quality and the child’s HMV mode predicted HRQoL and family functioning.

2.2 | Participants and settings

Parents of children with HMV therapy, aged between 0 and 18 years and with an ability to understand Swedish language, were included consecutively from December 2016 to December 2018. In total, 88 parents were included, and three questionnaires were incomplete which left 85 questionnaires from parents of 55 children for analysis. Paired data, from both mothers and fathers, were obtained from 30 families. Sixty parents were cohabiting, from the remaining 25 parents, either the mother or father responded to the questionnaire. Of these 25 parents, 12 were living on their own, 12 were married or cohabitating and one parent-reported other family conditions. Children with HMV in Sweden are usually treated in a respiratory clinic. These clinics were identified via a Swedish national quality register for oxygen and home respiratory treatment, Swedevox.\textsuperscript{2} Actual clinics were informed about the study and requested to ask parents of children with HMV about participation during a routine visit.

The study was approved by the Regional Ethical Review Board of Gothenburg, Sweden (Ref. No. 354-15). Parents were informed about the aim of the study, confidentiality and the voluntariness to participate which followed the guidelines of the Declaration of Helsinki.\textsuperscript{19}

2.3 | Measures

PedsQL Family Impact Module was developed to assess what impact a child’s chronic health condition has on the parents.\textsuperscript{20} The questionnaire consists of 36 items, and three summary scores can be derived: the Total Score (36 items), the Parent HRQoL Summary Score (20 items) and the Family Functioning Summary Score (eight items). The Parent HRQoL Summary Score is calculated by averaging the items from four scales measuring physical functioning (six items), emotional functioning (five items), social functioning
(four items) and cognitive functioning (five items). The Family Functioning Summary Score is a summative average of the following scales: daily activities (three items) and family relationships (five items). The Total Score is calculated by averaging the above 28 items together with items from the communication scale (three items) and worry scale (five items). The response format is a five-point Likert scale, in which items are scored from never a problem to always a problem to sleep. The scores are reversed and transformed into a zero to 100 scale, in which higher scores indicate better functioning. The validity and reliability are well documented. The Family Impact Module has been translated into Swedish and used in Swedish research. A linguistic validation into Swedish has been performed. The subscales were assessed for internal consistency reliability using Cronbach's alpha. The Total Score, the Parent HRQoL Summary Score and the Family Functioning Summary Score achieved values greater than 0.70.

Insomnia Severity Index is a seven-item self-reported questionnaire with documented reliability and validity for detecting insomnia. It has been translated into Swedish and used in population studies both nationally and internationally. The questionnaire evaluates the severity of sleep-onset (initial), sleep maintenance (middle) and early morning wakening problems (terminal) as well as sleep satisfaction, interference with daily functioning, noticeability of sleep problems and distress caused by sleep problems the last 2 weeks. The items are ranked on a five-digit Likert scale in which the items are scored from never a problem to always a problem and merged into a total score, which range from zero to 28; a score of ≥15 indicates clinically significant insomnia. The questionnaires were completed individually by each parent during a hospital visit and were placed in a sealed box.

2.4 | Statistical analyses

Descriptive statistics were used for background characteristics, PedsQL and ISI. Data were tested for normality, and since the criteria were met, parametric methods were used for analyses. The paired t test for comparison of mean values from PedsQL; Total Score, Parent HRQoL Summary Score, Family Functioning Summary Score and insomnia score, was used to analyse differences between the cohabiting mothers and father. Differences between parents' HRQoL Summary Score and Family Functioning Summary Score were explored in relation to HMV mode using one-way ANOVA. Insomnia Severity Index reports were dichotomised, <15 and ≥15, according to the defined cut-off values. The associations between the mother's and father's reports were analysed by chi-square test in relation to HMV mode, working as PCA or working as an employee outside the home. Linear multiple regressions with backward selection were used to predict the relationships between the dependent variables parents' HRQoL Summary Score and Family Functioning Summary Score. The independent variables were gender, parents working as PCA or not, parents having paid work outside the home or not, HMV mode and insomnia scores. The criteria for linear multiple regression (normality, linearity and homoscedasticity) were controlled and satisfactorily met. Regression models were evaluated using the adjusted $R^2$. A significance level was set to $P < .05$. IBM SPSS Statistics version 25 was used for the analyses.

3 | RESULTS

A total of 88 parents to 55 children responded to the questionnaires. Paired data, from both mothers and fathers, were obtained from 30 families, altogether 60 cohabiting parents. Three questionnaires were incomplete and were excluded which left 85 for the analysis: 45 from mothers and 40 from fathers. Both parents filled in the questionnaire for 30 children, in the other cases (n = 25), either the mother or father did. The background characteristics of parents and children are presented in Tables 1 and 2. The parents' mean age was 41 years; 41 years for mothers and 43 years for fathers. The children's mean age was 8.5 years, and the mean time in HMV treatment was 6 years and 8 months. The largest group had noninvasive ventilation treatment (n = 31).

### TABLE 1 Characteristics of parents to children receiving home mechanical ventilation (HMV)

| Participants (n = 85) | n (%) |
|----------------------|------|
| Mothers              | 45 (53) |
| Fathers              | 40 (47) |
| Age (n = 85)         | Mean (SD) |
| Parents              | 41 (6) |
| Mothers              | 41 (6) |
| Fathers              | 43 (6) |
| Education (n = 85)   | n (%) |
| Elementary school father/mother | 2 (5)/3 (6) |
| High school father/mother       | 18 (46)/20 (44) |
| University father/mother         | 19 (48)/20 (44) |
| Other father/mother         | 0 (0)/2 (4) |
| Employment (n = 84) | n (%) |
| Employment father/mother     | 35 (92)/36 (81) |
| Full time work father/mother  | 26 (68)/10 (22) |
| Father or mother working as a PCA | 49 (60) |
| Father working as PCA/mother working as a PCA | 21 (55)/28 (63) |
| Family characteristics (n = 55) | n (%) |
| Parents living together with each other | 60 (71) |
| Having two or more children (n = 53) | 44 (83) |
| Having a PCA employed (n = 53) | 46 (86) |
| Having two PCAs in tandem (n = 52) | 14 (27) |
| PCA hours/week (n = 55) mean (SD) | 123 (72) |

Abbreviation: PCA, personal care assistant.
Parents' HRQoL and family functioning are presented in Table 3. The mean values within the HRQoL dimensions ranged between 49 and 70; the lowest values were found for mothers' physical, emotional and social functioning, and the highest values were for fathers' cognitive functioning. Overall, and for most dimensions, there were no significant differences within the couples' HRQoL. The only differences found were within physical and cognitive functioning (Table 3).

The mean values within the family functioning dimensions ranged between 40 and 57; the lowest values were found for mothers' daily activities, and the highest values were found for family relationship rated by the fathers (Table 3). There were no differences within the couples' ratings of family functioning.

The parents' reports of insomnia are presented in Table 4. Dichotomisation of the scale scores showed that 25% of parents reported insomnia scores ≥15, indicating moderate to severe insomnia (Table 4). The chi-square test showed no differences between mothers' and fathers' perceived sleep problems.

There were no associations between parents' insomnia scores, the child's HMV mode ($X^2[3, N = 82] = 1.270, P = .788$) and whether the parents worked as a PCA ($X^2[2, N = 82] = 1.450, P = .518$) or had a paid work outside the home or not ($X^2[2, N = 82] = 0.962, P = .673$). There was a difference between the parents' HRQoL Summary Score ($F[2, 81] = 4.641, P = .012$) and the Family Functioning Summary Score ($F[2, 82] = 3.737, P = .028$) in relation to HMV mode. A Tukey post hoc test revealed significant differences between the HMV modes tracheotomy, noninvasive ventilation and CPAP according to the parents' HRQoL Summary Score and Family Functioning Summary Score. Being parent to a child with tracheotomy was associated with lower HRQoL ($m = 38.9$) and Family Functioning ($m = 37.5$) compared to noninvasive ventilation (HRQoL Summary Score [$m = 52.9$], Family Functioning Summary Score [$m = 54.3$]) and CPAP (HRQoL Summary Score [$m = 58.8$] and Family Functioning Summary Score [$m = 57.6$]).

The multiple linear regression analyses (Tables 5 and 6) showed that the basic model with the five independent variables was a significant predictor of parents' HRQoL Summary Score, explaining 46% of the variance ($R = .682$). The adjusted $R^2$ value in the regression model indicated that 45% of the variability in the dependent variable Parent HRQoL Summary Score was predicted by the child's HMV mode and parents' insomnia scores (Table 5). The child's HMV mode and ISI total score were also found to predict Family Functioning Summary Score, explaining 21% of the variance (Table 6).

### TABLE 2 Characteristics of children receiving home mechanical ventilation (HMV)

| Characteristics of children receiving HMV (n = 55) | Mean (SD) |
|-------------------------------------------------|-----------|
| **Age**                                         | 8.5 (4)   |
| **Diagnostic category (n = 52)**                 | n (%)     |
| Neuromuscular disease                            | 12 (23)   |
| Central apnoea                                   | 11 (21)   |
| Sleep apnoea                                     | 5 (9)     |
| Chromosomal aberrations                          | 9 (17)    |
| Other                                           | 15 (28)   |
| **HMV mode (n = 53)**                            | n (%)     |
| CPAP                                            | 13 (24)   |
| NIV                                             | 31 (58)   |
| Tracheotomy                                      | 9 (17)    |
| **Time with HMV (n = 52)**                       | n (%)     |
| HMV part of the day                              | 13 (25)   |
| HMV day or night                                 | 5 (9)     |
| HMV day and night                                | 28 (53)   |
| HMV 24 h                                        | 6 (11)    |
| Number of months with HMV treatment (n = 53)     | mean (SD) |
|                                                 | 73 (54)   |
| **Level of education (n = 52)**                  | n (%)     |
| Pre-school                                      | 8 (18)    |
| Elementary school                                | 31 (70)   |
| High school                                      | 5 (11)    |
| Home teaching                                    | 0 (0)     |

Abbreviations: CPAP, continuous positive airway pressure; NIV, noninvasive ventilation.

### 4 | DISCUSSION

There were no differences between mothers' and fathers' HRQoL Summary Score and Family Functioning Summary Score. Overall, differences were only found within physical and cognitive functioning. Parents' reports of HRQoL might be understood from the medical status of their children, which often requires advanced homecare that parents in many ways are responsible for. To the best of our knowledge, there is a lack of comparable summary scores for HRQoL and Family Functioning. Two studies were thus identified: parents of children with medical technology and parents of children with type 1 diabetes. In the study by Caicedo, 84 primary caregivers of children dependent on medical technology reported a HRQoL Summary Score of 50 and a Family Functioning Summary Score of 47. In that study, 69% of the children had more than one medical device, 24% had tracheotomy and 10% had ventilator. This may explain the slight differences in our outcomes of reported HRQoL Summary Score of 52 and Family Functioning Summary Score of 51. Furthermore, higher HRQoL Summary Score and Family Functioning Summary Score were reported by parents of children with type 1 diabetes. Different disease contexts may explain this difference; parents of children with HMV handle a complex responsibility where the underlying diseases often require lifelong multidisciplinary management where the HMV treatment represents one aspect. Other factors also have to be considered; previous research has shown that not only the severity of the child's underlying medical condition but also how parents cope with the situation plays
In addition, good social support has been associated with better mental health and cognitive, social, and family functioning in parents of children with HMV. The results showed that one of four parents reported moderate to severe insomnia. The child's HMV mode and the parents' sleep quality predicted parents' HRQoL. The size and direction of this relationship underscored that being a parent to a child with tracheotomy and having sleep problems significantly affected HRQoL. This seems understandable, since children with tracheostomy often have complex disease conditions that involve multiple medical technologies requiring continuous monitoring day and night. Previous research has also strengthened such a relationship and has showed that having a child being dependent on medical technology increased the parental care burden, resulting in daily fatigue and little energy for household tasks or social activities. Sleep problems had the strongest relationship with HRQoL. This may not be surprising, since previous research has described parental caregiving in this context as comparable to working rotating shift at different nights of the week. Deficient and instable sleep has been shown to negatively affect health outcomes, which deserves attention, considering that 25% of the parents in this study reported moderate or severe clinical insomnia.

Mothers reported clinical insomnia to a greater extent than the fathers. This trend may indicate that having a medically fragile child with functional limitations may affect mothers' HRQoL to a greater extent. However, no significant differences between mothers' and fathers' HRQoL, family functioning or sleep were found. Statistical power might be an explanation to this finding, but the results may also reflect that parents have to support each other to make everyday life work. Consequently, the situation can be demanding and affect HRQoL, family functioning and sleep for both parents, regardless of gender.

### TABLE 3 Mothers' and fathers' reports of health-related quality of life and family functioning

| Scales                          | Items | Parents (total) | Mothers | Fathers | Differences between parents | P-value |
|---------------------------------|-------|----------------|---------|---------|----------------------------|---------|
|                                 |       | n | Mean (SD) | n | Mean (SD) | n | Mean (SD) |                      |         |
| Total score<sup>a</sup>         | 36    | 84 | 54 (19) | 45 | 51 (20) | 39 | 57 (19) | .331                |         |
| Parent HRQoL summary score<sup>b</sup> | 20    | 84 | 52 (19) | 45 | 47 (20) | 39 | 57 (18) | .064                |         |
| Physical functioning            | 6     | 84 | 54 (22) | 45 | 49 (22) | 39 | 60 (21) | .043                |         |
| Emotional functioning           | 5     | 84 | 51 (21) | 45 | 49 (21) | 39 | 55 (21) | .656                |         |
| Social functioning              | 4     | 84 | 51 (25) | 45 | 49 (27) | 39 | 54 (24) | .833                |         |
| Cognitive functioning           | 5     | 84 | 62 (26) | 45 | 54 (29) | 39 | 70 (19) | .009                |         |
| Communication                   | 3     | 84 | 55 (24) | 45 | 55 (23) | 39 | 55 (26) | .430                |         |
| Worry                           | 5     | 85 | 52 (20) | 45 | 53 (20) | 40 | 51 (26) | .226                |         |
| Family functioning summary score<sup>c</sup> | 8     | 85 | 51 (23) | 45 | 50 (23) | 40 | 53 (24) | .881                |         |
| Daily activities                | 3     | 85 | 43 (26) | 45 | 40 (26) | 40 | 47 (27) | .435                |         |
| Family relationships            | 5     | 85 | 56 (26) | 45 | 55 (25) | 40 | 57 (27) | .798                |         |

<sup>a</sup>Summarising all items in the questionnaire (Parents PedsQL Family Impact Module Version 2.0).

<sup>b</sup>Summarising functional problems in physical, emotional, social and cognitive scale.

<sup>c</sup>Summarising daily activities and family relationships.

<sup>d</sup>Differences between mothers and fathers living together with each other (30 fathers and 30 mothers).

### TABLE 4 Reported level of insomnia in parents to children receiving HMV

| Scale                  | Score | Parents | Mothers | Fathers | Differences between parents<sup>a</sup> | P-value |
|------------------------|-------|---------|---------|---------|----------------------------------------|---------|
|                        |       | n = 82  | n = 42  | n = 40  | n = 30                                 |         |
| Absence of insomnia    | 0-7   | 29 (35) | 12 (28) | 17 (42) |                                        |         |
| Subthreshold insomnia  | 8-14  | 32 (39) | 18 (42) | 14 (35) |                                        |         |
| Moderate insomnia      | 15-21 | 17 (20) | 10 (23) | 7 (17)  |                                        |         |
| Severe insomnia        | 22-28 | 4 (4)   | 2 (4)   | 2 (5)   |                                        |         |
| ISI total score <15    | <15   | 61 (74) | 30 (71) | 31 (77) | .227                                   |         |
| ISI total score ≥15    | ≥15   | 21 (25) | 12 (28) | 9 (22)  |                                        |         |

<sup>a</sup>Differences between mothers and fathers living together with each other (30 fathers and 30 mothers) (Insomnia Severity Index).

an important role for HRQoL. In addition, good social support has been associated with better mental health and cognitive, social, and family functioning in parents of children with HMV. The results showed that one of four parents reported moderate to severe insomnia. The child’s HMV mode and the parents’ sleep quality predicted parents’ HRQoL. The size and direction of this relationship underscored that being a parent to a child with tracheotomy and having sleep problems significantly affected HRQoL. This seems understandable, since children with tracheostomy often have complex disease conditions that involve multiple medical technologies requiring continuous monitoring day and night. Previous research has also strengthened such a relationship and has showed that having a child being dependent on medical technology increased the parental care burden, resulting in daily fatigue and little energy for household tasks or social activities. Sleep problems had the strongest relationship with HRQoL. This may not be surprising, since previous
**TABLE 5** Multiple regression models with Parent HRQoL Summary Score as the dependent variable (n = 85)

| Predictor                              | B     | β      | Std. Error | F   | Sig.  | t     | Adjusted R^2 |
|----------------------------------------|-------|--------|------------|-----|-------|-------|---------------|
| Model A                                | 13.795 | <0.001 | 0.705      |     |       |       |               |
| Gender (mother/father)                 | 2.426  | 0.062  | 3.438      |     |       |       |               |
| Parent working as a PCA (y/n)          | −5.321 | −0.132 | 3.445      | 1.545 |       |       |               |
| Parent has paid work outside the home (y/n) | 2.920  | 0.050  | 5.045      | 0.579 |       |       |               |
| HMV mode                               | −15.356 | −0.281 | 4.648      | −3.304 |       |       |               |
| ISI total score                        | −1.836 | −0.571 | 0.279      | −6.588 |       |       |               |
| Model B                                | 17.317 | <0.001 | 0.796      |     |       |       |               |
| Gender (mother/father)                 | 2.700  | 0.069  | 3.390      |     |       |       |               |
| Parent working as a PCA (y/n)          | −5.130 | −0.128 | 3.413      | −1.503 |       |       |               |
| HMV mode                               | −15.428 | −0.283 | 4.625      | −3.336 |       |       |               |
| ISI total score                        | −1.845 | −0.574 | 0.277      | −6.659 |       |       |               |
| Model C                                | 22.992 | <0.001 | 1.585      |     |       |       |               |
| Parent working as a PCA (y/n)          | −5.375 | −0.134 | 3.391      |     |       |       |               |
| HMV mode                               | −15.612 | −0.286 | 4.608      | −3.388 |       |       |               |
| ISI total score                        | −1.887 | −0.587 | 0.271      | −6.958 |       |       |               |
| Model D                                | 32.574 | <0.001 | 1.51       |     |       |       |               |
| HMV mode                               | −14.899 | −0.273 | 4.632      | −3.217 |       |       |               |
| ISI total score                        | −1.924 | −0.599 | 0.273      | −7.051 |       |       |               |

Abbreviations: PCA, personal care assistant; HMV, home mechanical ventilation; HMV mode, continuous positive airway pressure (CPAP), noninvasive ventilation (NIV) and tracheotomy; ISI, Insomnia Severity Index.

**TABLE 6** Multiple regression models with Family Functioning Summary Score as the dependent variable (n = 85)

| Predictor                              | B     | β      | Std. Error | F   | Sig.  | t     | Adjusted R^2 |
|----------------------------------------|-------|--------|------------|-----|-------|-------|---------------|
| Model A                                | 4.391 | <0.002 | 0.171      |     |       |       |               |
| Gender (mother/father)                 | −0.863 | −0.018 | 5.058      |     |       |       |               |
| Parent working as a PCA (y/n)          | −0.942 | −0.020 | 5.067      | −0.186 |       |       |               |
| Parent has paid work outside the home (y/n) | 0.194  | 0.003  | 7.421      | 0.026  |       |       |               |
| HMV mode                               | −18.727 | −0.286 | 6.837      | −2.739  |       |       |               |
| ISI total score                        | −1.413 | −0.366 | 0.410      | −3.446  |       |       |               |
| Model B                                | 5.565 | <0.001 | 0.170      |     |       |       |               |
| Gender (mother/father)                 | −0.845 | −0.018 | 4.975      |     |       |       |               |
| Parent working as a PCA (y/n)          | −0.930 | −0.019 | 5.009      | −0.186  |       |       |               |
| HMV mode                               | −18.732 | −0.286 | 6.787      | −2.760  |       |       |               |
| ISI total score                        | −1.413 | −0.366 | 0.407      | −3.476  |       |       |               |
| Model C                                | 7.509 | <0.001 | 0.202      |     |       |       |               |
| Parent work as a PCA (y/n)             | −0.853 | −0.018 | 4.956      | −0.172  |       |       |               |
| HMV mode                               | −18.675 | −0.285 | 6.734      | −2.773  |       |       |               |
| ISI total score                        | −1.400 | −0.363 | 0.396      | −3.532  |       |       |               |
| Model D                                | 11.396 | <0.001 | 0.213      |     |       |       |               |
| HMV mode                               | −18.562 | −0.283 | 6.658      | −2.788  |       |       |               |
| ISI total score                        | −1.406 | −0.364 | 0.392      | −3.583  |       |       |               |

Abbreviations PCA, personal care assistant; HMV, home mechanical ventilation; HMV mode, continuous positive airway pressure (CPAP), noninvasive ventilation (NIV) and tracheotomy; ISI, Insomnia Severity Index.
Parents of children with HMV are often responsible for the advanced homecare. This study’s results showed no differences between mothers’ and fathers’ overall HRQoL, family functioning or sleep reports. However, one of four parents reported moderate or severe insomnia, and the child’s HMV mode and parents’ sleep quality were related and predicted the parents’ HRQoL. These findings underscore the importance of evaluating parents’ sleep and being aware that invasive ventilation influences parental HRQoL and family functioning.

CONFLICT OF INTEREST
The authors have no conflict of interest to declare.

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