Systematic Reviews

PROTOCOL

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Mapping health-related quality of life of children and families receiving pediatric invasive home mechanical ventilation: a scoping review protocol

Keisha White Makinde[1*], Maysara Mitchell[1], Alexandra F. Merz[1] and Michael Youssef[1]

Abstract

Background Children utilizing invasive home mechanical ventilation (administered via tracheostomy tube) receive intensive care at home without the support of trained staff typically present in an intensive care unit; within the context of worsening home nursing shortages, much of the 24/7 care burden falls to families which are likely under supported. Prior reviews have explored the quality of life of children receiving various forms of mechanical ventilation, without addressing the impact on the family. Additionally, the literature inconsistently differentiates the unique experience of families with children using invasive home mechanical ventilation from non-invasive, which has lower morbidity and mortality and requires less nursing care in the home. Therefore, our study aims to explore and map the existing literature regarding the impact of invasive home mechanical ventilation on the child and family's quality of life. Identified gaps will inform future research focused on improving the family quality of life of children with invasive home mechanical ventilation.

Methods Five databases will be searched using keywords and controlled vocabulary to identify relevant studies: Ovid Medline, Embase, Scopus, and Cochrane Library. English language studies will meet inclusion criteria if they include primary research studies of children or families of children utilizing invasive home mechanical ventilation at home and assess quality of life. Children and young adults aged 0–25 years will be included. We exclude studies of hospitalized children, studies focused solely on healthcare professional experiences or clinical outcomes, and those focused on the period surrounding discharge from admission for tracheostomy placement. Two independent reviewers will screen studies at the title/abstract and full-text levels. Two independent reviewers will extract data from relevant studies. Disagreements will be resolved by an independent third reviewer. A targeted grey literature search will be performed utilizing ProQuest, clinicaltrials.gov, WHO trial registry, Google Scholar, and professional societies. Findings will be presented in tables and figures along with a narrative summary.

Discussion This scoping review seeks to map the literature and provide a descriptive report of the health-related quality of life of children using invasive home mechanical ventilation and their families.

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Keywords Child, Family, Invasive mechanical ventilation, Quality of life

*Correspondence:
Keisha White Makinde
keisha.w@wustl.edu
Full list of author information is available at the end of the article

Background

The number of children with medical complexity who utilize medical technology is growing [1–3]. This has resulted in increased survival and longer lifespan [4,5]—two quality metrics frequently used to assess the quality of healthcare received. Yet, stakeholders, payors, and patient advocates have highlighted the importance of quality of life as a critical metric that should also be used to determine the success or failure of a healthcare intervention [6–8]. Despite this, there has been a lag in the collection of quality of life indicators and integration into metrics for high-quality healthcare, particularly for new pediatric technologies [7,9]. This scoping review protocol focuses on quality of life in regards to a medical technology which provides the highest level of medical life support available in the home setting—pediatric invasive home mechanical ventilation (HMV).

Home mechanical ventilation is a vital intervention for children experiencing chronic respiratory failure, promoting respiratory stability and enhanced longevity in the comfort of a child's home. HMV has the potential to benefit children with respiratory conditions by improving alveolar ventilation, alleviating symptoms associated with chronic respiratory failure, improving blood gases, reducing morbidity and mortality, and enhancing the child's quality of life [10]. HMV can be administered either invasively or noninvasively. Non-invasive HMV (for instance bilevel positive airway pressure (BIPAP)) provides a lower amount of breathing support and is administered via mask. Conversely, invasive ventilation provides a much higher amount of breathing support and is administered via a surgically placed tracheostomy tube which connects to the breathing machine. Originally conceived for pediatric patients with isolated spinal injury or neuromuscular conditions 11, over time the use of invasive HMV has expanded to treat children with more complex diseases and multiple comorbidities. Typical pediatric patients utilizing invasive HMV may have primary lung diseases such as chronic lung disease of prematurity [12,13], underlying genetic conditions such as congenital central hypoventilation syndrome [14], and cardiopulmonary disease [4,13,15]. Invasive HMV is associated with a higher risk for morbidity, frequent and high acuity readmission, and higher mortality compared with non-invasive ventilation [4,16]. Any sudden loss of tracheostomy patency (e.g., mucus plug, accidental tracheostomy decannulation) or loss of ventilator function (e.g., loss of power in the home, unaddressed ventilator alarms) would be imminently life threatening. Due to the tenuousness of maintaining a patent airway, the American Thoracic Society guidelines recommends that optimal care for children with invasive home mechanical ventilation requires 24/7 hands-on nursing care in the home, two trained family caregivers living in the child's household, along with monitoring equipment and regular multidisciplinary clinic visits [8]. In reality, the extensive and unrelenting nursing shortages throughout the country [17,18] mean that much of the in-home care falls to parents and families creating a significant burden for which they are underprepared.

Parents of children who utilize HMV are expected to provide extensive and ongoing care for their child—administering medications, managing medical emergencies that may arise, and calling off from work when home nursing services are inaccessible. There are few studies that examine the impacts on the family for children with invasive HMV [19,20]. On preliminary search, available studies focus on the parent [19,21] with little information on siblings or how the family's functioning is impacted. Studies of HMV (including both invasive and non-invasive) highlight that a parent's assumption of the primary caregiver role for their ventilator-dependent child can exacerbate financial burdens [9,10], sleep deprivation [10], and anxiety, impacting the overall family quality of life [11]. Chan et al. and Wang and Barnard interviewed parents of children who utilize ventilators at home and expose the significant strain on personal and romantic relationships, lack of friends and supports, frequent needs to transition between parent and caregiver, and constant worry that the child might suddenly die [22,23]. Further complicating the situation, nearly half of parents of children with any medical technology use (ranging from nebulizers and glucose monitors to ventilators) endorse having a need for respite care within the past year, yet only half of those needing respite had their needs met, often due to lack of availability or cost [24]. Considering these are the lived experiences of families of mostly children with non-invasive ventilation, it is imperative to understand more about the family quality of life of children utilizing invasive home mechanical ventilation given its increased demands for nursing, family caregiving, and higher morbidity and mortality.

Health-related quality of life (HRQOL) is a multidimensional concept described by many scholars which can be thought of as an individual's outlook or perspective on life and its resultant satisfaction (or dissatisfaction) given the presence of a medical condition. This perspective is grounded in the context of the individual's culture and value systems which are related to their goals, expectations, and concerns [25]. For the purpose of this review, we focus on the health-related quality of life of children, adolescents, and young adults with invasive home mechanical ventilation. For this protocol, we focus on the following domains [26,27]: (1) physical functioning, (2) psychological functioning, (3) social functioning, (4) cognitive functioning, and (5) general well-being.

We use the theory of health-related family quality of life (HRFQOL) as coined by Radina et al. [28] as the unifying theory for this review; the theory (see Fig. 1) defines HRFQOL as the intersection between the patient's health-related quality of life and the family's quality of life. Health-related family quality of life (HRFQOL) comprises 3 concepts: emotional closeness, family sense of coherence, and family functioning (see Fig. 2). For this review, we focus on the concepts and sub-concepts delineated by Radina et al. (see Fig. 2).

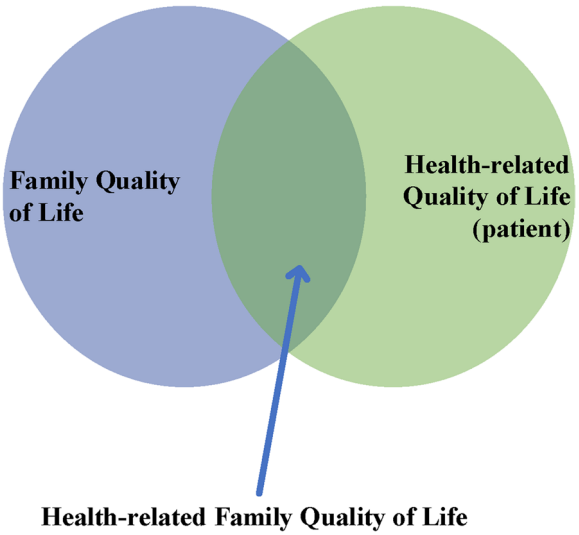

Fig. 1 Diagram of domains of quality of life

Family can have many definitions. For the purposes of this review, we draw upon the definition of family quality of life offered by Park et al. as "people who think of themselves as part of the family, whether related by blood or marriage or not, and who support and care for each other on a regular basis" [29].

Tracheostomy is a surgical airway management procedure whereby an incision is made in the trachea to divert the passage of air for breathing. Tracheostomy is used interchangeably with tracheotomy for the purposes of this review. Patients with a tracheostomy may breathe independently or with assistance of a ventilator. For this review, we focus on patients with tracheostomy who utilize mechanical ventilation.

Mechanical ventilation is a type of assisted breathing whereby a medical device (i.e., ventilator) is used to fully or partially provide artificial ventilation. Practically, the support can be positive pressure ventilation (pressure-supported ventilation or bilevel positive airway pressure (BiPAP) or continuous positive airway pressure (CPAP). For this review, we focus on any level of mechanical ventilation that is administered through a tracheostomy. Patients with isolated oxygen use without ventilator support will be excluded. Invasive mechanical ventilation refers to ventilation delivered through a breathing tube—an endotracheal tube or tracheostomy tube. For

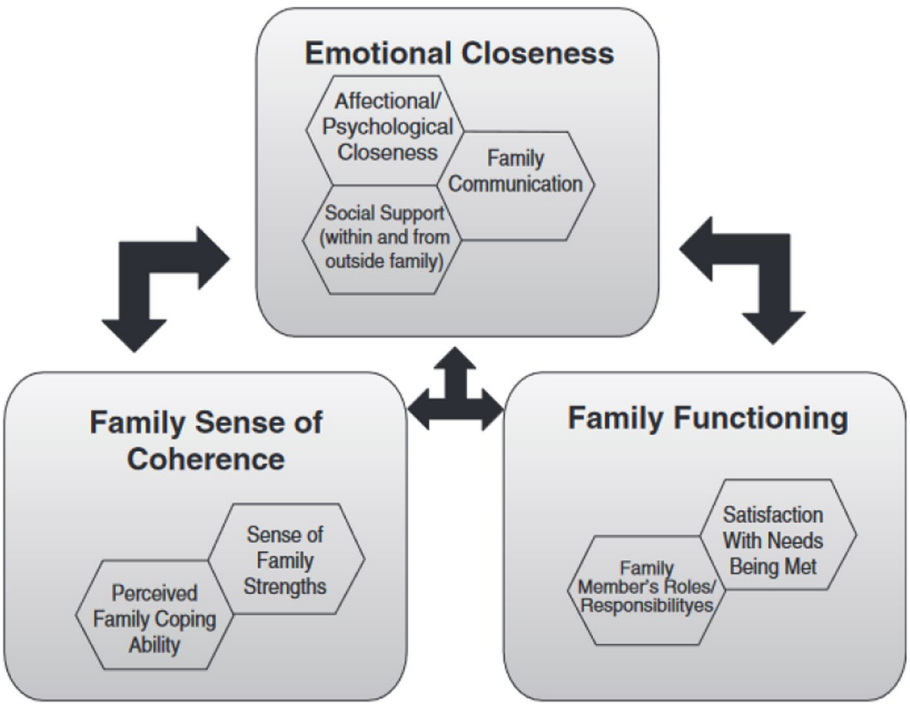

Fig. 2 Conceptual model of the theory of health-related family quality of life

the purpose of this review, we focus solely on invasive mechanical ventilation delivered via tracheostomy tube.

We define home as a location where the patient primarily lives with family. We exclude long-term care facilities in the definition of home for this study.

A preliminary search of PROSPERO, MEDLINE, the Cochrane Database of Systematic Reviews, and *JBI Evidence Synthesis* was conducted, and no current or in-progress scoping reviews or systematic reviews on this specific topic of interest. Mattson et al. [30] recently published a scoping review focused on quality of life of children with home mechanical ventilation; although informative, this review does not differentiate the experience of children living with invasive mechanical ventilation and their families. Our scoping review differs in two key ways. First, we focus on the family's quality of life instead of the child's quality of life. Secondly, we spotlight the experiences of children with invasive home mechanical ventilation, given their increased medically fragility, requisite home nursing needs, and higher risk of morbidity and mortality. Additionally, our review is strengthened by the use of a framework definition of health-related family quality of life from Radina et al. [28]which extends our focus beyond the challenges faced by parents to include the impact on the entire family unity, including siblings and extended family. By utilizing this approach and definition, we have preliminarily identified additional studies meeting our criteria which were not included in the review conducted by Mattson and colleagues, underscoring the differences in our search and screening approaches.

The existing literature predominantly focuses on mortality rates and medical outcomes of children utilizing HMV, with limited attention to the vital issue of family quality of life; though it is significantly impacted when intensive medical care is introduced in the home environment [31]. In addition to the few studies available, even fewer focus on family-level quality of life indicators or experiences of families with medically complex children. While previous scoping reviews have explored these concepts separately, no scoping review has reviewed both the health-related quality of life of the pediatric patient as well as the family quality of life of the overall family unit. Additionally, we aim to provide an updated overview of the literature, given the most recent scoping reviews assessed studies through 2020 [30,32].

The primary objective of this scoping review is to comprehensively map the existing literature on pediatric invasive mechanical ventilation in the home environment to understand the child's health-related quality of life (HRQOL) and the health-related family quality of life (HRFQOL).

Methods

Authors will utilize the *JBI Manual for Evidence Synthesis* Chapter 11 entitled "Scoping Reviews" as a guideline for rigorous procedures [33]. Authors will utilize the Preferred Reporting Items for Systematic Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) as a guideline for reporting the findings of the scoping review [34].

This review will consider primary studies that include pediatric patients (0–25 years) who utilize invasive HMV, as well as the experiences of their family members. Furthermore, this review will consider studies that explore (1) the relationship between pediatric invasive HMV and health-related family quality of life (HRFQOL), (2) the relationship between pediatric invasive HMV and health-related quality of life (HRQOL) among children, adolescents, and young adults and their families, and (3) studies that address the experiences of children who utilize home mechanical ventilation with a tracheostomy. Studies must be published in English from 2004 to 2024 to meet inclusion criteria. This review will consider studies that explore the presence of invasive mechanical ventilation in the home environment. Studies that address the presence of invasive mechanical ventilation in the healthcare setting or within long-term care facilities will not be included. This scoping review will consider quantitative, qualitative, and mixed methods study designs for inclusion.

The search strategy will aim to locate published primary studies and grey literature, excluding reviews, and text and opinion papers. An initial limited search of the literature was undertaken by the medical librarian to identify studies on the topic. The text words contained in the titles and abstracts of relevant studies, and the index terms used to describe the studies, were used to develop an initial search strategy for Embase. The search strategy, including all identified keywords and index terms, will be adapted for each included information source. The initial search strategy will be piloted and adapted in partnership with the medical librarian to develop the final search strategy (see Appendix 1). Studies published in an English publication between 2004 and 2024 will be included. The databases to be searched include Ovid Medline 1946-, Embase.com 1947-, Scopus 1823-, and Cochrane Library 1996-.

Following the search, all identified records will be collated and uploaded into Endnote v.21 (Clarivate Analytics, PA, USA) and Covidence (Veritas Health Innovation, Melbourne, Australia), and duplicates removed. Covidence will be used to screen and manage the results of the scoping review to optimize collaboration and thoroughness among the research team. Pilot testing of source selection will be conducted prior to screening. The primary investigator will select a random sample ($n=20$) of studies, which will be independently reviewed by all reviewers. Reviewers will screen the titles and

abstracts using the inclusion and exclusion criteria provided in Covidence. After all pilot studies have been reviewed, reviewers will meet to discuss inter-rater reliability. If reliability is > 75%, reviewers will proceed with Screening. If reliability does not reach 75%, reviewers will have an in-depth discussion regarding discrepancies. Inclusion and exclusion criteria will be modified to meet newly shared understanding. Then reviewers will separately pilot the revised criteria. The formal screening will proceed once 75% agreement is reached.

During screening, titles and abstracts will be assessed by 2 independent reviewers against the inclusion criteria. Reviewers 1 and 2 will independently assess the title and abstract of each article using Covidence's title and abstract screening feature. If there is disagreement among Reviewers 1 and 2, Reviewer 3—the primary investigator—will review the title and abstract to make the final determination on the article's eligibility. To ensure fidelity to protocol, the primary investigator will provide oversight and review a random selection of screenings completed by Reviewers 1 and 2 to confirm adherence to review protocol. Potentially relevant papers will be retrieved in full and imported into Covidence.

During full-text review, the full text of selected citations will be assessed in detail against the inclusion criteria by 2 independent reviewers. Reasons for exclusion of full-text papers that do not meet the inclusion criteria will be recorded and reported in Covidence. Any disagreements that arise between the reviewers at each stage of the selection process will be resolved through discussion or with a third reviewer. The results of the search will be reported in full in the final scoping review and presented in a PRISMA flow diagram [21]. To ensure fidelity to protocol, the primary investigator will provide oversight and review a random selection of full texts completed by Reviewers 1 and 2 to confirm adherence to review protocol.

Several sources will be used to inform the grey literature search, which will be an adaptation of methods described by Godin et al. 35. Utilizing keywords identified previously, we will search ProQuest Dissertations & Theses, National Library of Medicine clinical trials registry (clinicaltrials.gov), World Health Organization International Clinical Trials Registry Platform (trialsearch.who.int), Google Scholar, and relevant professional societies to identify clinical guidelines, dissertations and thesis, reports, and other findings from organizations that fit the inclusion criteria for this scoping review. The intention remains to identify and map the scientific literature and consensus statements from reputable sources while excluding sources with individualistic viewpoints, such as social media and blog postings.

Prior to the start of data extraction, the data extraction instrument will be pilot tested on 3 sources to ensure all relevant results are consistently extracted. Each reviewer will read the pilot studies and extract data using the extraction instrument in Covidence. Team members will then meet to discuss discrepancies, offer clarification, and make any modifications to the extraction instrument. Extraction will begin once consensus on the extraction instrument is reached.

Data will be extracted from papers included in the scoping review by 2 independent reviewers using a data extraction tool developed by the reviewers (see Appendix 2). The data extracted will include specific details about the population, concept, context, methods, and key findings, relevant to the review question. A draft extraction tool is provided (see Appendix 2). The draft data extraction tool will be modified and revised as necessary during the process of extracting data from each included paper. Modifications will be detailed in the full scoping review. Any disagreements that arise between the reviewers will be resolved through discussion or with a third reviewer. Authors of papers will be contacted to request missing or additional data, where required.

We will first present a flow diagram of our scoping review methodology including the study selection process. Extracted data will be analyzed using figures and tables, frequency counts of concepts, populations, and study characteristics. Then, we will utilize a table to present an overview of study characteristics including year, country, participant characteristics, and methodology. Lastly, we will present in a table an overview of themes and concepts elicited in the included studies.

Discussion

This scoping review has begun and is in the data selection phase at submission. Inclusion and exclusion criteria were revised following screening. Notably, we exclude conference abstracts; although these are often published in peer-reviewed journals, they many times do not include thorough details of the data and results to allow us to extract findings with confidence that they represent the true and full findings of the primary research. Additionally, conference abstracts often presented preliminary results which may have changed following the abstract acceptance. We conducted a search using the abstract first author to determine if a manuscript was available; none of our conference abstracts had corresponding manuscripts and thus were excluded. We also had several clinical trial registrations returned in our search protocol; these registrations were excluded from review; however, the authors contacted the clinical trial primary investigator to ascertain if the study had concluded and if a published manuscript was available; if manuscripts become available in the process, we will add them to title/abstract screening and perform screening consistent with the full protocol.

Appendix 1 Search strategy

Embase.

Search conducted on March 8, 2024.

Search	Query	Records retrieved
#1	"adolescence"/exp OR "child"/exp OR "preschool child"/exp OR "adolescent"/exp OR "pediatrics"/exp OR "juvenile"/exp OR "child":ti,ab OR "children":ti,ab OR "preschool child":ti,ab OR "preschooler":ti,ab OR "adolescent":ti,ab OR "teenager":ti,ab OR "teenagers":ti,ab OR "teen":ti,ab OR "teens":ti,ab OR "teenage":ti,ab OR "juvenile":ti,ab OR "juveniles":ti,ab OR "youth":ti,ab OR "youths":ti,ab OR "paediatric care":ti,ab OR "paediatrics":ti,ab OR "pediatric care":ti,ab OR "pediatrics":ti,ab OR babies:ti,ab OR baby:ti,ab OR boy:ti,ab OR boys:ti,ab OR girl:ti,ab OR girls:ti,ab OR infant:ti,ab OR infants:ti,ab OR kid:ti,ab OR kids:ti,ab OR newborn:ti,ab OR newborns:ti,ab OR pubescent:ti,ab OR "school child":ti,ab OR "school children":ti,ab OR schoolchild:ti,ab OR schoolchildren:ti,ab OR toddler:ti,ab OR toddlers:ti,ab AND "home"/exp OR "home":ti,ab OR "transitional home":ti,ab OR "household"/exp OR "domestic unit":ti,ab OR "household":ti,ab AND ("invasive ventilation"/exp OR "artificial ventilation"/exp OR "mechanical ventilator"/exp OR "invasive mechanical ventilation":ti,ab OR "home invasive mechanical ventilation":ti,ab OR "invasive home mechanical ventilation":ti,ab OR "invasive respiratory support":ti,ab OR "invasive ventilation":ti,ab OR "invasive ventilatory support":ti,ab OR "artificial respiration":ti,ab OR "artificial respiratory support":ti,ab OR "artificial ventilation":ti,ab OR "artificial ventilatory support":ti,ab OR "controlled respiration":ti,ab OR "controlled ventilation":ti,ab OR "mechanical respiration":ti,ab OR "mechanical ventilation":ti,ab OR "home mechanical ventilation":ti,ab OR "home mechanical ventilator":ti,ab OR "bt-v2s":ti,ab OR "elisee 150":ti,ab OR "life2000":ti,ab OR "plv-100":ti,ab OR "respironics v60":ti,ab OR "servo-air":ti,ab OR "servo-air niv":ti,ab OR "servo-i":ti,ab OR "servo-n":ti,ab OR "servo-s":ti,ab OR "servo-u mr":ti,ab OR "tangens 2c":ti,ab OR "trilogy 100":ti,ab OR "mechanical ventilator":ti,ab OR "mechanical ventilators":ti,ab) OR ("tracheostomy"/exp OR "open surgical tracheostomy":ti,ab OR "open tracheostomy":ti,ab OR "tracheostomy":ti,ab OR "tracheotomy":ti,ab OR tracheotomies:ti,ab) AND "quality of life"/exp OR "happiness"/exp OR "wellbeing"/exp OR "family conflict"/exp OR "family support"/exp OR "sibling relation"/exp OR "child parent relation"/exp OR "happiness":ti,ab OR "well being":ti,ab OR "wellbeing":ti,ab OR "wellness":ti,ab OR "family conflict":ti,ab OR "family conflicts":ti,ab OR "interparental conflict":ti,ab OR "interparental conflicts":ti,ab OR "marital conflict":ti,ab OR "marital conflicts":ti,ab OR "parent child conflict":ti,ab OR "parent child conflicts":ti,ab OR "family support":ti,ab OR "kin support":ti,ab OR "kinship support":ti,ab OR "sibling relation":ti,ab OR "sibling relations":ti,ab OR "sibling rivalry":ti,ab OR "child parent relation":ti,ab OR "child parent relationship":ti,ab OR "parent child relation":ti,ab OR "parent child relationship":ti,ab OR "parent infant bonding":ti,ab OR "parent infant relation":ti,ab OR "parent to child relation":ti,ab OR "parent to child relationship":ti,ab OR "parental role":ti,ab OR "parenting":ti,ab OR "family relations":ti,ab OR "family relationship":ti,ab OR "family relation":ti,ab OR "family relationships":ti,ab OR fqol:ti,ab OR "hrql":ti,ab OR "health related quality of life":ti,ab OR "life quality":ti,ab OR "quality of life":ti,ab OR "health related family quality of life":ti,ab OR "health-related quality of life":ti,ab OR "hr fqol":ti,ab OR "family harmony":ti,ab OR "family happiness":ti,ab OR "family life satisfaction":ti,ab)	409

Appendix 2 Data extraction instrument

	Description	Extracted Data
General Information		
Study ID	LastName YYYY. LastName1 and LastName2 YYYY. LastName1 et al YYYY	
Title	full title	
Lead Author Contact	Name, email	
Country of Origin	Options: USA, UK, Canada, Other	
General Notes		
Characteristics of Included Studies		
Study Aims		
Study Type	Qualitative, Quantitative, Mixed Methods	
Study Design	Options: Interventional Design, cohort study, cross sectional, case-control study, case series, case study, ethnography, phenomenology, other	
Unit of Analysis	Options: Child with HMV, Parent, Sibling, Additional family member, other	
Participant Inclusion Criteria		
Participant Exclusion Criteria		
Recruitment Method	Options: Phone, Social Media, Clinic/hospital patient records, online support group, in person support group, Other	
Funding Source		
Noted Conflicts of Interest for study authors		

Participants

	Number	%	Age Range (years)	Age Central Tendency (mean, median, mode; specify)
Children w/HMV				
Parents of children with HMV				
Siblings of children with HMV				
Other family members				
Total Number of Participants		100		

Race	Number	%
Black		
White		
Asian		
American Indian or Alaska Native		
Native Hawaiian or Other Pacific Islander		
Unknown		
Race not specified by authors		

Ethnicity	Number	%
Hispanic		
Non-Hispanic		
Unknown		
Ethnicity not specified		

Language	English, Spanish, Other, not specified	
Did authors examine any socioeconomic variables (ex: income, neighborhood quality, insurance type)?	Yes, No	
Did this study look at a single patient population?	Options: yes, no	
What medical comorbidities did participants have?	Options: Muscular disorder, Pulmonary disease, airway disorder, cardiac disease, cancer, neurologic disorder, traumatic brain injury, other	
Analysis		
Domains of HRQOL (child) measured	Options: Physical functioning, psychological functioning, social functioning, cognitive functioning, general wellbeing, None	
Domains of HRFQOL (family) measured	Options: Psychological and/or affective closeness, Family communication, Social support, Perceived family coping ability, Sense of family strengths, satisfaction with needs being met, family members' roles or responsibilities, None	
Scales and Measures Utilized	Options: None, PedsQL, CHRI, Pediatric Inventory for Parents, Life Satisfaaction Scale, Family APGAR, Other, None	
If a Scale(s) was used, was the entire scale used or was there a subscale?	Options: Entire Scale used, subscale used, not specified, no scales used, other	
Analytic Method Utilized	Options: Descriptive, statistical-bivariate, statistical-multivariate, content analysis, thematic analysis, constant comparative method or grounded theory, phenomenological/hermaneutical, not specified, other	
Results		
How were the results measured? List all concepts/themes elicited in the results section (this item only refers to qualitative studies)		
Describe any key findings that relate to this review topic		
What were the author's conclusions? Limitations		
Notes on reviewer's interpretation of results		
Notes on reviewer's interpretation of article strength/weaknesses		

Abbreviations

BiPAP	Bilevel positive airway pressure
CPAP	Continuous positive airway pressure
HRQOL	Health-related quality of life
HRFQOL	Health-related family quality of life
HMV	Home mechanical ventilation
PRISMA-ScR	Preferred Reporting Items for Systematic Meta-Analyses extension for Scoping Reviews

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Authors' contributions
Keisha White Makinde participated in the conception and design of this protocol, drafting and revision of manuscript, and approval of final version. Maysara Mitchell participated in the conception and design of this protocol, drafting and revision of manuscript, and approval of final version. Alexandra Merz participated in the design of this protocol, revision of manuscript, and approval of final version. Michael Youssef participated in the design of this protocol, revision of manuscript, and approval of final version.

Authors' information
Dr. KWM is a pediatric hospice and palliative medicine physician-scientist interested in understanding racial and ethnic health disparities and promoting health equity in patients facing serious illness. Dr. KWM has extensive educational background focused on the biopsychosocial experiences of individuals with illness, including a bachelor's degree in Sociology and Medicine, Health, and Society and Master of Public Health. As an attending physician, Dr. KWM cares for children with serious illness including children who utilize home mechanical ventilation seen at St. Louis Children's Hospital with a focus on interdisciplinary, family-centered, holistic care.

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Availability of data and materials
Data sharing is not applicable to this article as no datasets were generated or analyzed during the current study.

Declarations

Ethics approval and consent to participate
Not applicable, no human subjects.

Consent for publication
Not applicable.

Competing interests
The authors declare that they have no competing interests.

Author details
[1]Washington University in St. Louis School of Medicine, 660 South Euclid Avenue, MSC 8116-0043-08, Saint Louis MO 63110-1010, USA.

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