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Parent education programs for children assisted by invasive mechanical ventilation: A scoping review

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ABSTRACT

Problem: The population of children assisted by invasive mechanical ventilation (IMV) and living at home is growing. Although parent education is essential for safe transitions from hospital-to-home, little is known about how this education is delivered. The aim of this review is to identify existing literature about parent education programs, synthesize the evidence, and identify gaps in the literature for future inquiry.

Eligibility criteria: This scoping review was conducted in accordance with the Joanna Briggs Institute methodology. Full-text publications in the English language focused on describing parent education programs for children assisted by IMV, indexed in CINAHL, PubMed, OVID, and PsycINFO and published from 2010 to 2021 were included. Reference lists of relevant articles were reviewed, and a hand search was completed to locate any additional literature outside the original search.

Sample: A total of 2472 citations were identified. After screening titles and abstracts, 37 full-text articles were retrieved and assessed for eligibility. Two independent reviewers completed the screening process. A hand search located one additional article. A final sample of 18 articles were included in the review.

Results: The parent education programs described in the final sample included standardized discharge education programs, simulation training, resourcefulness training, patient-specific action plans, disaster preparedness, and symptom and technology management.

Conclusion: Although most parent education programs identified in this review focused on teaching caregiver skills, program characteristics and outcome measures varied widely.

Implications: This review recommends directions for future research to optimize parent education for children assisted by IMV.

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Introduction

The population of children who are assisted by invasive mechanical ventilation (IMV) has been growing due to advances in health care and improved medical technology that enables children with complex health care needs to live at home (Gowans et al., 2007; Muesing et al., 2020). Children with IMV require specialized medical equipment, continuous cardiorespiratory monitoring provided by a nurse or trained caregiver, and follow-up care from a multidisciplinary health care team. While children assisted by IMV once lived primarily in hospitals

or long-term care settings, they are now able to safely transition from hospital-to-home with their families. However, the process of transitioning home remains challenging. Parents of children with complex medical needs report taking on additional roles, such as that of a health care provider, case manager, student, teacher, and advocate (Woodgate et al., 2015).

Because of these expanded and essential parental roles for a child to live safely in the family home instead of the hospital, parent education is a critical element of discharge planning for children who are transitioning home with IMV. In 2016, the American Thoracic Society released an evidence-based clinical care guideline for pediatric chronic home invasive ventilation that includes educational objectives for family and professional caregivers (Sterni et al., 2016). To meet these objectives, the guidelines describe that parents must demonstrate knowledge

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and skill mastery related to pulmonary and tracheostomy care, emergency response, ventilator management, medications, monitoring and assessment (Sterni et al., 2016).

Parents of children with tracheostomies and IMV assistance describe a challenging transition home (Amar-Dolan et al., 2020; Callans et al., 2016; Mai et al., 2020). While they may be adequately prepared for routine care, parents have reported gaps in the training they receive before discharge and the realities of providing care at home (Amar-Dolan et al., 2020). Parents have proposed that initial web-based video training, peer connections, group meetings, and ongoing training opportunities would be helpful to them as they learn to assume primary responsibility for their child's care (Callans et al., 2016; Mai et al., 2020).

Despite general guidelines on educational objectives, there is great variability in training between programs, and standards are lacking. Furthermore, to our knowledge, no systematic or scoping review has previously been published on parent education programs for children assisted by IMV. The objective of this scoping review is to identify existing literature about parent education programs for children assisted by IMV, provide an overview of the evidence, and identify gaps in the literature for future inquiry. This scoping review will address the following questions: (1) What programs have been used to deliver parent education for children assisted by IMV? (2) What are the characteristics of these programs (e.g. duration, teaching method, program leads)? and (3) What parent, child, and/or family outcome variables are used to measure the effectiveness of these parent education programs?

Methods

Design

The scoping review was conducted in accordance with the Joanna Briggs Institute (JBI) methodology for scoping reviews and the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Review (PRISMA-ScR) Checklist (Peters et al., 2015; Peters MDJ et al., 2020; Tricco et al., 2018).

Information sources and search strategy

Search strategies were developed iteratively in consultation with a professional medical librarian (AF). The following electronic databases were searched on January 12, 2021: CINAHL Plus with Full Text (EBSCO), PubMed, Ovid Medline, and PsycINFO (EBSCO). Results were limited to English language only. The search strategies were tailored to each database combining keyword and controlled vocabulary terms. The search strategy for CINAHL Plus with Full Text is represented in Table 1. A final hand search and review of reference lists from relevant articles was completed as part of the search strategy. A grey literature search strategy was not developed as a component of this scoping review due to the volume of literature available from peer-reviewed sources. Given the robust nature of publications on this topic, the authors decided to focus the search as described above.

Eligibility criteria

Participants

This review considered studies that included parents or family caregivers of children of all ages assisted by IMV. Although these parents did not need to be the exclusive targets of the education program, the sample must have been documented to include at least one parent. In cases where it was unclear from the demographic characteristics reported in the study if any parent had a child assisted by IMV, but it seemed probable, original authors were contacted to confirm eligibility.

Table 1
CINAHL plus with full text (EBSCO) search strategy.

#	Query	Results
1	(MH "Child" OR MH "Pediatrics" OR child* OR paediatr* OR pediater AND ((MH "Respiration, Artificial" OR (MH "Ventilator Patients" OR (MH "Ventilators, Mechanical") OR ("home mechanical ventilation" OR "invasive ventilation" OR "medical complexity" OR "medically complex" OR "medically fragile" OR technology dependent" OR "ventilator dependent"	12,533
2	MH ("Child, Medically Fragile)	1125
3	1 or 2	12,533
4	(MH "Caregivers") OR (MH "Parents") OR (caregiver* OR family OR families OR father OR mother* OR parent*)	575,470
5	(MH "Patient Education") OR (MH "Parenting Education") OR (MH "Support, Psychosocial") OR (MH "Support Groups") OR (MH "Caregiver Support") OR (educat* OR intervention* OR program* OR train* OR support*)	1,885,059
6	3 AND 4 AND 5	1225
7	3 AND 4 AND 5 Narrow by Language: -English	1188
8	7 Narrow by Published Date: 20100101-	704

Note. Date of Search: January 12, 2021.

Concept

Research papers that reported the development, implementation, or evaluation of parent education programs were eligible for inclusion in this review. Parent education programs included those described as interventions, programs, or support services that provided education or training to parents or family caregivers.

Context

Studies conducted in any geographic location and in any setting (e.g. inpatient, outpatient, or home) were considered for this review.

Types of studies

All publications utilizing qualitative, quantitative, or mixed methods were considered eligible. Non-empirical studies such as reviews or commentaries and non-English language publications were excluded. Published conference abstracts were also excluded because their brevity excluded essential detail and publications did not include a peer review process. Search results were narrowed to those published in 2010 and later to identify the most contemporary approaches to parent education for children assisted by IMV.

Screening and data extraction

All citations retrieved from the databases were first imported into Endnote 20 (Clarivate Analytics, PA, USA) and then uploaded to Covidence (Veritas Health Innovation, Melbourne, Australia) for deduplication and screening. Titles and abstracts were independently reviewed against the selection criteria in a blinded process by two reviewers of the research team (MH and SH). The remaining citations were then reviewed as full-text articles for inclusion against the selection criteria again by two reviewers (MH and SH). A third reviewer (SS) was consulted to resolve discrepancies.

A data extraction tool was created by all members of the team and data extraction was completed independently by two reviewers (MH and SH). Variables included: author(s), year of publication, title of publication, journal, study aim/purpose, study design, sample size, child characteristics, parent characteristics, program description, eligibility criteria for education program, program leads, program setting, mode of program delivery, underlying program framework, program duration, outcome measures, limitations, and key findings. These variables were selected to address the review questions. Any extracted data discrepancies were resolved by reviewer consensus or in consultation with senior members of the review team (SS and WJ).

Synthesis of results

Extracted data were organized into two generated tables (Table 2: Characteristics of Included Studies and Parent Education Programs and Table 3: Primary Outcome Measures) to display an overview of the parent education programs identified in the literature. Studies are presented alphabetically by the first author's last name with full citations included in the reference list. The tables were used to develop consensus narrative summaries of the main results. We have organized the findings based on the review questions.

Results

Identification of parent education programs

A total of 2472 records were identified through the systematic search of the four databases previously described. After removing 775 duplicates, a total of 1697 records were screened. Based on the title and abstract, 1660 records were excluded, and 37 full-text articles were assessed for eligibility. If it was unclear if the study population included children assisted by IMV after full-text review, the corresponding author was attempted to be contacted for clarification. Of the 37 full-text articles retrieved, 20 were excluded for the following reasons: eight were not considered to be original qualitative, quantitative or mixed-methods research (e.g.; review articles, commentaries), five did not describe a parent education program, five did not explicitly state or an author did not confirm that the child population included children assisted by IMV, and two were conference abstracts. Of the five that did not describe a parent education program, one described the development of an informational booklet for parents of children assisted by IMV which included educational material (Edwards et al., 2020). However, the primary goal of this booklet was to support decision-making on IMV initiation instead of parent education for children with IMV, and therefore this article was excluded.

The remaining 17 articles were considered eligible for this review along with one additional article found during the hand search. Thus, the final sample consisted of 18 studies reporting the development, implementation, or evaluation of parent education programs for children assisted by IMV. Fig. 1 depicts the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram for the search and screening process (Page et al., 2021).

Seven of the 18 included studies reported on the standardization of discharge processes which included education for parents (Baker et al., 2016; Gaudreau et al., 2016; Kohn et al., 2019; McCasland & Brooks, 2019; Szondy et al., 2014; Tolomeo et al., 2017; Van Orne et al., 2018). Educational resources provided to parents in these programs included road maps, customized training calendars, caregiver skills checklists, standardized emergency supply bags, classes, instruction booklets and videos. While there are overlapping features of these programs, variability in the training curricula exists. For example, one pediatric respiratory care unit that serves children assisted by IMV created a 12-week standardized family education program to be completed before discharge from inpatient care with weekly topics that included basic infant care, safe handling, respiratory assessment, tracheostomy care, and home ventilator training (Szondy et al., 2014). At another pediatric medical center, a structured pre-discharge training program for caregivers to be completed in the hospital was developed that included nine sessions with progressive skills training until the caregiver is able to provide all patient care at the bedside in the final session (Van Orne et al., 2018).

Six of the 18 studies reported on simulation programs that were designed to teach parents and caregivers routine and emergency management skills necessary to safely care for a child assisted by IMV at home (Boroughs, 2017; Prickett et al., 2019; Thrasher et al., 2018; Tofil et al., 2013; Whalen, 2020; Yuen et al., 2021). Most simulation-based education was reported to occur in conjunction with other discharge training and usually occurred in a simulation lab led by a trained simulation facilitator. In one simulation-based discharge program,

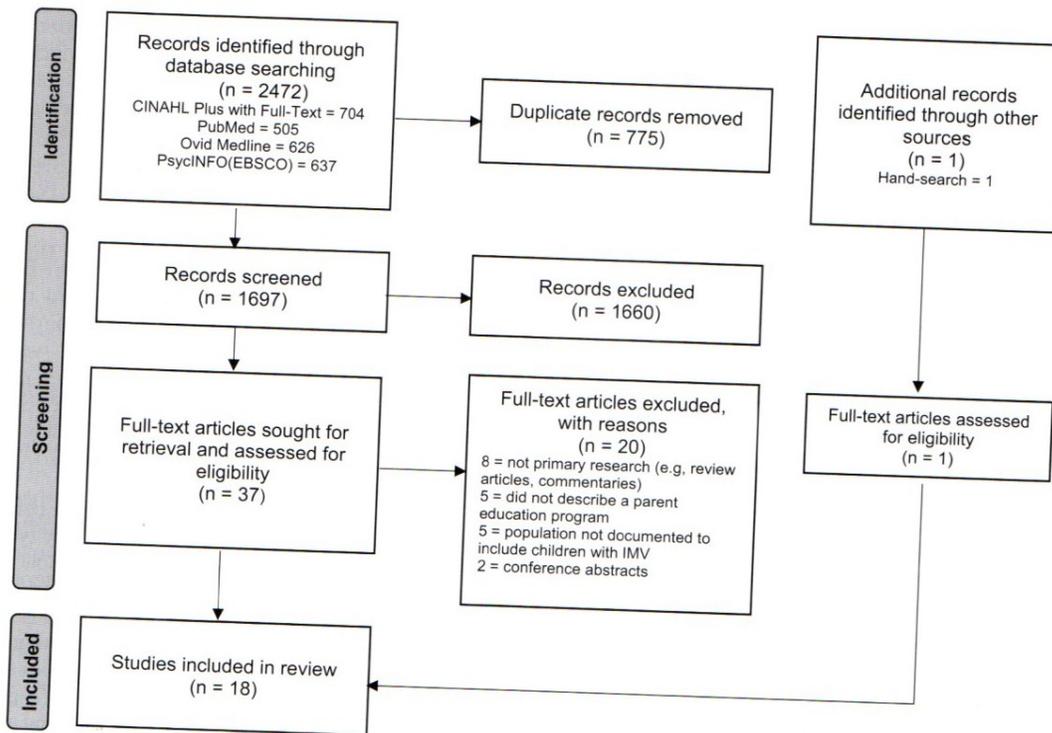


Fig. 1. Preferred reporting items for systematic and meta-analyses (PRISMA) flow diagram.

parents participate as early as one week after tracheostomy placement to begin learning core tracheostomy management skills (Yuen et al., 2021). Other programs use simulation to assess parent skill acquisition over time (Whalen, 2020) or before discharge (Tofil et al., 2013). In most of these programs, a high-fidelity mannequin and home equipment was used for the simulation scenarios and debriefing with the parent followed. Emergency scenarios included desaturation events, mucus plugging, accidental decannulation, ventilator alarms and troubleshooting, manual resuscitation, and cardiopulmonary resuscitation (Prickett et al., 2019; Thrasher et al., 2018; Tofil et al., 2013; Yuen et al., 2021). One community-based simulation education program was developed to meet the continuing education needs of parents of children with Spinal Muscular Atrophy. In this program, simulated emergency scenarios for parents of children assisted by IMV included decannulation, ventilator malfunction, respiratory distress, power outage, and cardiopulmonary resuscitation (Boroughs, 2017). Another simulation-based discharge program included peer-to-peer support during the initial training and for a six month period afterwards (Yuen et al., 2021). These family advisors were experienced parents of children utilizing a medical device who volunteered to provide peer support after receiving specialized training from social workers and child life specialists. During the initial training and follow-up period, family advisors helped ensure the educational content was delivered at an appropriate level, addressed parent questions and anxieties, and assisted as a family advocate.

Two studies reported on a resourcefulness training intervention for mothers (Boebel Toly et al., 2016; Toly et al., 2014). This cognitive-behavioral intervention aimed to improve mental health outcomes for mothers of technology-dependent children by teaching and reinforcing personal and social resourcefulness skills (Toly et al., 2014). Using the acronym "RESOURCE" as a memory aid, mothers were taught the following resourcefulness skills: "rely on family/friends, exchange ideas with others, seek professionals or experts, organize daily activities, use positive self-talk, reframe the situation positively, change from usual reaction, and explore new ideas" (Boebel Toly et al., 2016, p. 270). The remaining three studies reported on programs that delivered parent education focused on (1) patient-specific medical action plans to follow post-discharge (Coller et al., 2018), (2) disaster preparedness in case of a prolonged power failure or need for evacuation (Gillen & Morris, 2019), and (3) symptom and technology management (Spratling et al., 2020).

Program characteristics

Although all 18 included studies had at least some parents of children assisted by IMV, only two studies exclusively had this patient population (Thrasher et al., 2018; Tofil et al., 2013). The samples of children that included children with IMV were also described as children with chronic ventilation, technology-dependence, medical complexity, tracheostomies, long-term ventilation in the home, or Spinal Muscular Atrophy. In most studies, both parents and primary caregivers were invited to participate in the education program. The resourcefulness training intervention was the only program to invite only mothers of technology-dependent children living at home (Boebel Toly et al., 2016; Toly et al., 2014).

The duration of the training program and length of follow-up time varied widely. The shortest initial training time reported was 15 min for a focused review of a disaster preparedness checklist (Gillen & Morris, 2019). The longest reported program time was 12 weeks for a standardized discharge program (Szondy et al., 2014; Tolomeo et al., 2017). There was also variation in duration reported within programs. For example, in one structured training program, caregivers must satisfactorily complete each training session before progressing to the next session and the average time to complete discharge training was 16 days (Van Orne et al., 2018). While the primary caregiver received an initial training schedule, ultimately the training time varied based on

each caregiver's availability and skills. In addition, some programs were reported to occur over the patient's length of stay (Baker et al., 2016; McCasland & Brooks, 2019).

Seven of the parent education programs included in this review identified a theoretical framework used in the development of the programs – Promoting Excellence and Reflective Learning in Simulation (Prickett et al., 2019), Kolb's Theory of Experiential Learning (Thrasher et al., 2018), Malcolm Knowles' Tenets of Andragogy (Tofil et al., 2013), Zauszniewski's resourcefulness theory (Toly et al., 2014), adult learning theory (Whalen, 2020) and a program which used a combination of self-regulation theory, control theory, and the emotional contagion hypothesis (Spratling et al., 2020).

Program educators were often a solo nurse or a nurse within the program team ($n = 13$). Other educators included respiratory therapists, ventilator care program staff, a medical home physician, a PICU fellow, trained simulation facilitators, and general pediatricians trained in simulation-based education.

These programs were primarily delivered inpatient ($n = 8$) and some occurred in a combination of inpatient, outpatient, and home settings ($n = 5$). Other settings included the simulation lab ($n = 4$) and online ($n = 1$).

Program outcomes

Included studies in this review measured parent and child outcomes. The majority of studies ($n = 14$) collected data on a parent outcome. These outcomes measured data related to caregiving skills (Boroughs, 2017; Whalen, 2020), training time (McCasland & Brooks, 2019; Szondy et al., 2014; Tolomeo et al., 2017; Van Orne et al., 2018), satisfaction (Boroughs, 2017; Prickett et al., 2019; Van Orne et al., 2018), comfort (Prickett et al., 2019), confidence (Boroughs, 2017; Tofil et al., 2013), an aggregate measure for comfort and confidence (Yuen et al., 2021), stress (Van Orne et al., 2018), preparation (Gillen & Morris, 2019; Tofil et al., 2013), and efficacy of the training (Thrasher et al., 2018; Toly et al., 2014). Three pilot studies used parent responses to study feasibility, acceptability, fidelity, usefulness, and ease of use (Boebel Toly et al., 2016; Spratling et al., 2020; Toly et al., 2014).

Studies with primary child and child healthcare outcomes ($n = 8$) measured data related to length of hospital stay (Baker et al., 2016; Coller et al., 2018; McCasland & Brooks, 2019; Tolomeo et al., 2017; Van Orne et al., 2018), readmission (Coller et al., 2018; Gaudreau et al., 2016; Thrasher et al., 2018), complications and adverse events (Gaudreau et al., 2016; Kohn et al., 2019), identifiable supply issues (Kohn et al., 2019), and developmental assessment referrals (Tolomeo et al., 2017). No studies used a family-based outcome measurement tool.

A review of the findings demonstrates that most studies reported positive changes in measured outcomes. However, not all these changes reached the level of statistical significance. In descriptive qualitative investigations, parents and caregivers generally provided positive responses to open-ended survey questions. Description of primary outcome measures and findings for all studies are summarized in Table 3.

Discussion

This scoping review was conducted in order to describe the state of parent education programs for children assisted by IMV. Among the 18 studies included, we found that the goal of most education programs was to prepare parents with the appropriate knowledge and skills to safely transition from hospital-to-home. This was accomplished with standardized discharge processes incorporating educational materials and supply checks, simulation training and education, web-based modules on symptom and technology management, and shorter educational sessions focused on resourcefulness training, patient specific action

Table 2
 Characteristics of included studies and parent education programs for children assisted by IMV (N = 18).

Author (year) Title	Study design	Study Aim	Parent and/or child characteristics	Parent education programs			Setting(s)	
				Duration	Theory	Components		
Baker et al. (2016) A Standardized Discharge Process Decreases Length of Stay for Ventilator-Dependent Children	Pre- and post-intervention comparison	To investigate the impact of a standardized discharge process within an interdisciplinary Ventilator Care Program	48 children after initiation of chronic ventilation	Length of stay (143 days, post-intervention overall hospital LOS mean)	None identified	<ul style="list-style-type: none"> Standardized discharge process included: <ul style="list-style-type: none"> Steps of Chronic Ventilation Road Map Discharge materials Instructional videos Caregiver skills checklist Emergency simulation modules Two required family care conferences Resourcefulness training intervention with journaling <ul style="list-style-type: none"> Face-to-face session to teach eight social and personal resourcefulness skills Journal writing on the application of resourcefulness skills Wallet-sized reminder card for resourcefulness skills Weekly phone calls from the interventionist 	Advanced practice nurse, rehabilitation respiratory therapist, and VCP team	ICU and Pediatric Respiratory Care Unit
Boebel Toly et al. (2016) Journaling as Reinforcement for the Resourcefulness Training Intervention in Mothers of Technology-Dependent Children	Secondary analysis of a Randomized Control Trial	To determine the feasibility, acceptability, and fidelity of journaling to reinforce a resourcefulness training intervention	22 mothers of children, living at home, who were dependent on medical technology	50 min initial session with 4 weeks of journaling and 5–10 min weekly phone calls	None identified	<ul style="list-style-type: none"> Registered nurse specializing in pediatrics 	Outpatient and home	
Boroughs (2017) An Evaluation of a Continuing Education Program for Family Caregivers of Ventilator-Dependent Children with Spinal Muscular Atrophy	Pre- and post-intervention comparison with survey and open-ended questions	To evaluate the effectiveness of a community-based training curriculum	13 family caregivers of 11 children diagnosed with Spinal Muscular Atrophy who are assisted by either non-invasive ventilation or invasive ventilation via a tracheostomy	4 h initial lab training and 2 h follow-up home visit	None identified	<ul style="list-style-type: none"> Community-based training curriculum included: <ul style="list-style-type: none"> Pre-test Caregiver performed un-coached response to simulation scenarios Debriefing and remediation with direct instruction and coaching from simulation educators Repeated simulation scenarios In-home visit by family's clinical manager 	Nurse simulation educators, 3-month follow-up by clinical manager, 6-month follow up by project manager	Nursing agency's simulation lab and home
Coller et al. (2018) Complex Care Hospital Use and Postdischarge Coaching: A Randomized Controlled Trial	Randomized controlled trial	To examine the effect of a caregiver coaching intervention on hospital use	147 children with medical complexity and their caregivers	Meeting before discharge, home visit, and 3 phone calls post-discharge 10 days	None identified	<ul style="list-style-type: none"> Plans for Action and Care Transitions intervention included: <ul style="list-style-type: none"> Patient-specific action plans Post-discharge coaching 	Medical home physician or nurse practitioner and nonclinical transition coach	Inpatient and outpatient
Gaudreau et al. (2016) Preventing Complications of Pediatric Tracheostomy Through Standardized Wound Care and Parent Education	Case series and medical record review	To determine the effect of a postoperative protocol for parent education and wound care on readmissions and complications	191 children who underwent tracheostomy at a tertiary pediatric medical center	15 min initial assessment and follow-up at 2 weeks and 6 months	None identified	<ul style="list-style-type: none"> Post-operative tracheostomy care and education protocol outlining educational objectives from pre-op to POD 7–9 	Nurse trained in tracheostomy care	Inpatient
Gillen and Morris (2019) Preparing Families of Technology-Dependent Children for Emergencies	Single arm, survey-based study	To characterize baseline level of emergency preparedness and determine if an ICU-based planning intervention sustainably improves disaster preparedness	Parents of 50 technology-dependent children admitted to a PICU	Not identified	None identified	<ul style="list-style-type: none"> Review of disaster preparedness checklist and educational follow-up to increase capacity for care during a prolonged power failure 	PICU Fellow	PICU
Kohn et al. (2019)	Pre- and	To describe the	292 children with	Not identified	None identified	<ul style="list-style-type: none"> Education provided with distribution of a 	Respiratory	Inpatient

Standardization of Pediatric Tracheostomy Care with "Go-bags"	post-intervention comparison	standardization of pediatric tracheostomy emergency supplies and demonstrate the impact on tracheostomy-related adverse events	tracheostomies	Pre-trach meeting through length of stay	None identified	standardized tracheostomy "Go-bag" which contained all labeled emergency supplies	therapists, Home Ventilation Program staff, and nurses	and outpatient
McCasland and Brooks (2019) Multidisciplinary Team Approach Improves Patient Outcomes in Tracheostomy Patients: A Clinical Initiative	Pre-intervention retrospective chart review and prospective post-intervention data collection	To describe the implementation and evaluation of a standardized education approach	68 participants in pre-intervention group 7 children in the post-intervention phase, 4 of which were ventilator-dependent	Pre-trach meeting through length of stay	None identified	Standardized tracheostomy education included: • A pre-trach meeting • Classes for tracheostomy care and tube change, ventilator management, and CPR • Return demonstration of daily cares • Caregiver Rooming-in • Tracheostomy journey board outlining steps before discharge home • Customized calendar • Tracheostomy and ventilator instruction books	Clinical nurse specialist, nurse, respiratory therapist, and social worker	Inpatient
Prickett et al. (2019) Simulation-based Education to Improve Emergency Management Skills in Caregivers of Tracheostomy Patients	Pre- and post-intervention comparison	To test the impact of simulation on confidence and management skills	39 caregivers of pediatric patients who were planned for discharge home with new tracheostomy	2 h	Promoting Excellence and Reflective Learning in Simulation	High-fidelity simulation-based tracheostomy and ventilator management workshop	Trained simulation facilitator	Simulation lab or other educational space
Spratling et al. (2020) Establishing Fidelity for the Creating Opportunities for Personal Empowerment: Symptom and Technology Management Resources (COPE-STAR) Intervention	Intervention and feasibility study using a quasi-experimental one group design	To test the fidelity and usability of the COPE-STAR intervention	5 caregivers were recruited from the Technology Dependent Pulmonary Clinic, all children required a tracheostomy and one child required mechanical ventilation	Average review time was 5–10 min per module, 6 modules total	Self-Regulation Theory, Control Theory, Emotional Contagion Hypothesis	Creating Opportunities for Personal Empowerment: Symptom and Technology Management Resources (COPE-STAR) Intervention focuses on educational support for children aged 1–5 who commonly experience respiratory symptoms and fever • Six web-based modules with focus on teaching symptom management Stepping Stones to Home, a 12-week program with weekly goals and topics covering: • Basic infant care • Safe handling • Respiratory assessment • Tracheostomy care • Home ventilator training Educational resources included calendars, skills checklists, scenarios, extended stays, and comprehensive care days	None (web-based modules)	Online
Szondy et al. (2014) Standardizing Family Education in a Pediatric Respiratory Care Unit	Pre- and post-intervention comparison with retrospective review	To describe the implementation and impact of a revised caregiver education program	Caregivers for 10 children with a tracheostomy tube, with and without ventilator-dependence in intervention group	12 weeks	None identified	Stepping Stones to Home, a 12-week program with weekly goals and topics covering: • Basic infant care • Safe handling • Respiratory assessment • Tracheostomy care • Home ventilator training Educational resources included calendars, skills checklists, scenarios, extended stays, and comprehensive care days	Nurses	Pediatric Respiratory Care Unit
Thrasher et al. (2018) A Quality Improvement Initiative to Implement High-fidelity Simulation Training for Caregivers of Children Requiring Long-term Mechanical Ventilation	Prospective pre- and post-simulation surveys	To incorporate high-fidelity simulation training into a multimodal curriculum, investigate the impact, and determine which curricular elements were most useful	87 family caregivers of 47 children requiring long-term mechanical ventilation in the home	Not identified	Kolb's Theory of Experiential Learning	High-fidelity simulation of tracheostomy and ventilator-related emergencies was incorporated into a multimodal discharge training curriculum	Ventilator Care Program educator and simulation program staff	Inpatient simulation facility
Toflil et al. (2013) Ventilator Caregiver Education through the Use of High-fidelity Pediatric Simulators: A Pilot Study	Post-intervention survey	To assess parents' response to the addition of simulation training to the Home Ventilator Program	15 home ventilator families	60–90 min	Malcolm Knowles' Tenets of Andragogy	Caregiver simulation training incorporated into the six-week home ventilator program included: • Skills practice with high-fidelity simulators	Home Ventilator Program registered nurse educators, respiratory therapists, and simulation experts	Simulation lab

(continued on next page)

Table 2 (continued)

Parent education programs								
Author (year) Title	Study design	Study Aim	Parent and/or child characteristics	Duration	Theory	Components	Educator(s)	Setting(s)
Tolomeo et al. (2017) Standardizing Care and Parental Training to Improve Training Duration, Referral Frequency, and Length of Stay: Our Quality Improvement Project Experience	Retrospective chart review	To standardize care and skills proficiency training before discharge home	12 infants in the post-intervention group in study period 1 received the welcome binder and 8 infants in the post-intervention group received education materials	12 weeks	None identified	<ul style="list-style-type: none"> • Debriefing • Emergency reference card • A multidisciplinary model of care approach was developed to include education focused on the: <ul style="list-style-type: none"> • NICU to Pediatric Respiratory Care Unit • Transition • Developmental assessments • Standardized rehabilitation services • Preparation checklists • Tracheostomy FAQ handouts 	Multidisciplinary Pediatric Respiratory Care Unit team	Pediatric Respiratory Care Unit
Toly et al. (2014) Resourcefulness Training Intervention: A Promising Approach to Improve Mental Health of Mothers with Technology-dependent Children	Randomized controlled pilot trial	To determine the feasibility, acceptability, and efficacy of the resourcefulness training intervention	22 mothers of children living at home, who were dependent on medical technology	50 min initial session with 4 weeks of journaling and 5–10 min weekly phone calls	Zauszniewski's resourcefulness theory	<ul style="list-style-type: none"> • Resourcefulness skills training for social and personal skills included: <ul style="list-style-type: none"> • In-person teaching of 8 resourcefulness skills • Laminated card and magnet with skills listed 	Nurse	Outpatient and home
Van Orne et al. (2018) Boot Camp for Caregivers of Children With Medically Complex Conditions	Quasi-experimental pre- post-test design	To determine the effectiveness of a structured boot camp-style discharge training program	34 primary caregivers of children with medically complex conditions and newly placed tracheostomies	Not identified	None identified	<ul style="list-style-type: none"> • Predischarge "Boot Camp" training program for caregivers • Nine structured sessions • Caregivers must progress in order 	Nurse	Inpatient
Whalen (2020) The Feasibility and Use of Simulation to Assess Parent Learning	Descriptive quantitative design	To assess parent learning and confidence after sequential simulation sessions	8 parents of children with a tracheostomy, 6 of 8 children were ventilator dependent	4- to 8- weeks	Adult learning theory	<ul style="list-style-type: none"> • Parent Airway Assessment with Simulation Program intervention included: <ul style="list-style-type: none"> • Laminated resource cards that outlined skills with illustrations • Focused assessment of clinical skills • Debriefing 	Not specified	Inpatient and home
Yuen et al. (2021) Simulation-Based Discharge Education Program for Caregivers of Children With Tracheostomies	Pilot study with pretest- post-test quasi-experimental design	To describe the design, implementation, and evaluation of simulation-based education	25 caregivers of 15 children with tracheostomies 24 caregivers included in analysis because one had an incomplete evaluation despite follow-ups attempted	Initial session (3 h) and 6 months of follow-up peer support	None identified	<ul style="list-style-type: none"> • Simulation-based Discharge Program included: <ul style="list-style-type: none"> • Simulation-based education session focused on teaching routine and emergency tracheostomy skills • Peer-to-peer support following the SBE session 	General pediatricians or nurses with previous SBE experience	Inpatient

Table 3
Primary outcome measures and findings for articles describing parent education programs for children assisted by IMV (N = 18).

Author (Date)	Primary outcome measures	Findings
Baker et al. (2016)	Overall length of stay (LOS) Pediatric respiratory care unit LOS	Overall LOS decreased by 42% (p = .002) Unit LOS decreased by 56% (p = .001)
Boebel Toly et al. (2016)	Feasibility of journaling Acceptability of journaling Fidelity of journaling	19/22 mothers completed journal writing Mothers reported that journaling helped reinforce resourcefulness skills Mothers had mixed views on specific aspects of journaling Resourcefulness skills were used in journaling
Boroughs (2017)	Change in pre-test to post-test score Caregiver satisfaction Caregiver confidence 3-month post-training skill assessments 6-month post-training satisfaction	12/13 caregivers improved scores All caregivers reported satisfaction or high satisfaction with the training techniques All caregivers reported increased confidence in caregiving All caregivers were evaluated to be proficient in caregiver skills All caregivers reported the training to be beneficial
Coller et al. (2018)	Hospitalization 30-day readmission	Hospitalization lower for PACT group in adjusted analyses (p = .04) Readmission lower for PACT group in adjusted analyses (p = .05)
Gaudreau et al. (2016)	Rate of readmission Rate of tracheostomy-related wound complications	No difference in readmission (difference 0.2%; 95% CI -12.5 to 13%) Significant decrease in tracheostomy-related wound complications (difference 13.7%; 95% CI 1.6 to 26%)
Gillen and Morris (2019)	Disaster preparedness checklist completion	Disaster preparedness checklist completion rates were higher at each follow-up time point compared to baseline (p < .001)
Kohn et al. (2019)	Number of identifiable issues found with go-bag checks Number of inpatient-tracheostomy related adverse events	185 go-bag checks identified need for supply replacement No statistically significant difference in inpatient-tracheostomy related adverse events after distribution of go-bags
McCasland and Brooks (2019)	Mean time to starting education in intervention group Mean hospital LOS for ventilator-dependent patients	Mean time to initial education was shorter in intervention group (4.5 days vs 18 days in pre-intervention group) Mean hospital LOS for ventilator-dependent patients was shorter in intervention group (45 days vs 89 days in pre-intervention group with ventilator and non-ventilator dependent patients)
Prickett et al. (2019)	Change in caregiver comfort for managing desaturation Change in caregiver comfort for managing mucous plugging Change in caregiver comfort for managing decannulation	Mean increase 9 mm on a 10 cm Visual analog scale (95% CI 3.0–14 mm) Mean increase 16 mm (95% CI 8.0–23 mm) Mean increase 10 mm (95% CI 3–17 mm) Simulations were realistic and helpful
Spratling et al. (2020)	Discharge survey Usefulness of COPE-STAR Ease of use of COPE-STAR Acceptability of COPE-STAR	All agreed or strongly agreed that the intervention was useful (range = 98–100% per module) All agreed or strongly agreed that the intervention was easy to use (range = 85–92% per module) All agreed or strongly agreed that the intervention was acceptable (range = 92–100% per module)
Szondy et al. (2014)	Caregiver training time	80% of caregivers completed training in 12 weeks or less post-intervention, 39% of caregivers completed training in 12 weeks or less pre-intervention
Thrasher et al. (2018)	Perceived efficacy of study components Patient readmissions within 7 days of discharge	Post-simulation debriefing was perceived as more beneficial compared to simulation scenarios (p = .002), CPR training (p = .011), education videos (p = .000) and printed educational handouts (p = .000) No statistically significant improvement in patient readmissions
Tofil et al. (2013)	Caregiver reported preparation Caregiver reported confidence	71% of caregivers strongly agree that they were prepared to care for their child at discharge 86% of caregivers strongly agreed that simulator training resulted in more confidence
Tolomeo et al. (2017)	Time required for parents to achieve proficiency in care Length of stay for infants Referral of infants for developmental assessment	50% (6 of 12) of families completed training within 12 weeks in period 1 Length of stay was 151.9 days compared to 157.3 days in the pre-intervention group in period 1 75% (9 of 12) of infants received developmental assessments compared to 0% in pre-intervention group in period 1
Toly et al. (2014)	Feasibility of the resourcefulness training Acceptability of the resourcefulness training (RT) Efficacy of the RT on mother's mental health outcomes	86.1% study response rate suggests RT was feasible Content analysis of exit interview transcripts suggests RT was acceptable Medium effect size of intervention at 6 weeks on Negative Emotion Checklist (d = 0.52) and small effect size on Depressive Cognition Scale (d = 0.22)
Van Orne et al. (2018)	Patient length of stay in TCU (mean) Discharge training time (mean) Caregiver stress (median) Caregiver satisfaction	Lower LOS for bootcamp group (92 vs 60 days; p = .02) Lower discharge training time for bootcamp group (60 vs 16 days; p < .001) Lower caregiver stress for boot camp group (49 vs 45; p < .001) Positive survey responses to open-ended questions
Whalen (2020)	Skill levels across content	Families demonstrates significant increase in skill levels across content (p = .006)
Yuen et al. (2021)	Pre- and post- simulation-based education (SBE) surveys measuring self-reported comfort and confidence Skills assessment checklist for tracheostomy care skills	Significant improvement in comfort and confidence reported in post-SBE surveys (p < .001) Significant improvement in checklist assessment of tracheostomy care skills (p < .001)

plans, and disaster preparedness. Most programs provided training before the child's discharge home but there were some that occurred outpatient or provided follow-up after discharge home. The longest reported follow-up time was six months. In addition to variability in

training curricula and program characteristics, we also found that program outcome measures varied widely. Among the studies included in this review, parent and child outcomes were used to measure the effectiveness of the education delivered.

Despite the variability in existing parent education programs, this scoping review identified several characteristics which were common among programs. First, pediatric nurses often have an essential role in providing education to parents of children assisted by IMV. Most studies included in this review utilized a nurse, solely or as part of the program team, to deliver education to parents. This education involved pre-discharge training as well as education in the outpatient or home setting. This is an important nursing responsibility as the delay in training or inadequate training can have negative impacts on patient outcomes and length of stay. In one cohort study of pediatric patients with new tracheostomy and ventilator dependence, the second most common reason for discharge delay after index hospital admission was parent training (Sobotka, Foster, et al., 2019). In addition, parent perspectives on the factors leading to re-hospitalization for children with medical complexity suggest that the decision to seek emergent care is influenced by parents' comfort level in taking care of the child at home (Nelson et al., 2016; Sobotka et al., 2020). Thus, it is essential for pediatric nurses to provide the most effective instruction to prepare parents for home care and to consider parental preferences when designing an effective education program. A qualitative study describing the family experience of the hospital-to-home transition with a child with a tracheostomy found that caregivers reported it was easy to engage and learn from health care providers who demonstrate competence, confidence, attentiveness, and patience (Callans et al., 2016). Nurses in these educator roles should display these characteristics.

Our analysis identified several gaps and areas for future research to optimize parent education so that children assisted by IMV can flourish in the home setting. Almost all included studies focused on education programs that provided caregiver skills training in areas of medical or nursing care, such as ventilator training, emergency preparedness, etc. This is consistent with the recommended educational objectives for family caregivers outlined in the American Thoracic Society's evidence-based clinical care guideline (Sterni et al., 2016). Families are often discharged with limited home nursing support, and parents or primary caregivers must be prepared to fulfill all aspects of a child's medical care at any time of day (Maynard et al., 2019; Sobotka, Gaur, et al., 2019). This includes managing a tracheostomy and home ventilator, administering tube feedings and medications, and providing close monitoring of the child. However, previous research has also documented that parents of technology-dependent children report significant alterations in their parenting identity and in the parent-child relationship (Kirk et al., 2005). Parents have described how nursing activities can dominate their parenting experience and change the structure of family life and home (Kirk et al., 2005). One mother said, "I was like a full-time nurse, I wasn't like a mother. That got to me... I didn't even know him as a mother – I'm his nurse you know" (Kirk et al., 2005, p. 540). In another qualitative study exploring the family experience of pediatric home ventilation, families discussed feeling unprepared for daily family life and the impact of home ventilation on relationships with others (Henderson et al., 2021). Including this anticipatory guidance in parent education programs has the potential help meet the social and emotional needs of parents who are navigating many complex roles. Further, children assisted with IMV have high rates of neurodevelopmental disability (Com et al., 2013; DeMauro et al., 2014; Gowans et al., 2007) and little is known about how parents understand and address developmental concerns. Since few of the parent education programs identified in this review were documented to include additional education on other parenting topics such as growth and development or address the impact of technology on the parent-child relationship, this may represent another opportunity to optimize the education provided to parents and strengthen parenting in the setting of disability.

Additionally, there may also be opportunities to increase the accessibility of these educational programs. Only one program in this review, the Creating Opportunities for Personal Empowerment: Symptom and Technology Management Resources, utilized digital delivery methods which consisted of six web-based modules compatible with mobile

devices (Spratling et al., 2020). Since parents of children assisted by IMV may experience logistical barriers in attending face-to-face educational sessions due to conflicting work and childcare responsibilities, adopting the use of digital delivery methods may enhance the reach and impact of these programs. A systematic review of digital delivery methods used to implement evidence-based parenting training interventions provides initial evidence to support their efficacy in improving outcomes for parents and children (Breitenstein et al., 2014). Furthermore, the provision of technology-based educational materials is likely to align with parent preferences. In a recent study of new mothers' preferences for parent education materials, technology-based materials were preferred (Raines & Robinson, 2020). However, this research did not include parents of children assisted by IMV and additional research investigating the acceptability and usefulness of digital delivery methods for educating this parent population is needed. Incorporating parents' input into the design, implementation, and evaluation of programs delivering parent education is a necessity.

In sum, additional research is needed to support the design and test the effectiveness of parent education programs for children assisted by IMV. The variability of parent and child outcome measures reported also make it difficult to compare the effectiveness across programs. Standardizing the assessment of parents' knowledge and skills as well as incorporating a measure of ongoing competency would make it easier to make meaningful comparisons across programs. In addition, only two programs, Plans for Action and Care Transitions and a resourcefulness training intervention, were tested using a randomized controlled trial (Coller et al., 2018; Toly et al., 2014). Many of the other programs were developed in the context of quality improvement initiatives and were tested using pre- and post-intervention comparisons with convenience samples. Small sample sizes, while expected due to the overall size of this population, also limited the statistical analysis. When randomized controlled studies are not possible, investigators should continue to seek rigorous study designs incorporating ideas from prior studies and programs. The initial positive findings reported in this review suggests there is preliminary evidence to support the design and optimization of parent education programs for children assisted by IMV.

Limitations

This scoping review was conducted with recognized methodology from the Joanna Briggs Institute and in accordance with the PRISMA-ScR Checklist (Peters et al., 2015; Peters MDJ et al., 2020; Tricco et al., 2018). Our search strategy, which was developed iteratively with a professional medical librarian (AF), attempted to balance sensitivity and specificity. However, we acknowledge some limitations. First, the search strategy was pragmatically limited to studies published in the English language because of the reviewers' language skills. Second, the search was limited to 2010 and later to identify contemporary parent education programs, which may have resulted in the exclusion of some relevant studies published before this time. Third, the search did not utilize the search term "tracheostomy" as the intent was to find parent education specifically for children assisted by invasive ventilation which would have also included technology management and home nursing support. Finally, in the screening stage, there were some challenges in determining if the study sample included parents of children assisted by IMV as not all studies directly documented this. In cases where it was unclear but seemed probable, original study authors were contacted. A final hand search and review of reference lists from relevant articles was completed. While we are unable to guarantee that studies haven't been missed, and we suspect that there are other parent education programs for children of IMV that can be found in the grey literature, we believe a rigorous search was undertaken for this review.

In accordance with scoping review methodology, a critical appraisal of included studies was not completed. The research evidence included in this review was largely descriptive and quasi-experimental. Small

sample sizes, convenience sampling, and limited reporting of parent and child characteristics limit the conclusions that can be drawn between the programs and outcomes measured. Despite these limitations, this scoping review provides a valuable contribution to the evidence on parent education programs for children with IMV and points to areas for future research and program development.

Conclusions

This review describes the characteristics and outcomes of formalized parent education programs reported in the literature for parent education programs for the care of children with IMV. Although most parent education programs identified in this review focused on teaching caregiver skills and utilized nurses as main educators, other program characteristics and selected outcome measures varied widely. The results of this review may be beneficial to nurses and health care providers looking to design, implement, and evaluate education programs for parents of children assisted by IMV. As this population continues to grow, the optimization of these education programs has important consequences for the health and well-being of children assisted by IMV and their families.

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Credit authorship contribution statement

Michelle S. High: Conceptualization, Methodology, Investigation, Writing – original draft, Writing – review & editing, Project administration. **Wrenetha Julion:** Conceptualization, Methodology, Writing – review & editing, Supervision. **Sarah Heigel:** Investigation, Writing – review & editing. **Andrea Fawcett:** Methodology, Resources, Writing – review & editing. **Sarah A. Sobotka:** Conceptualization, Methodology, Writing – review & editing, Supervision.

Declaration of Competing Interest

The authors have no conflict of interest to declare.

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