Seminars in Fetal and Neonatal Medicine 24 (2019) 101042

Contents lists available at ScienceDirect

Seminars in Fetal and Neonatal Medicine

journal homepage: www.elsevier.com/locate/siny

Preparing families to care for ventilated infants at home

Dan Benscoter[a,b,*], Adrienne Borschuk[a,c], Catherine Hart[d], Kristin Voos[e,f]

[a] Department of Pediatrics, University of Cincinnati, College of Medicine, 3333 Burnet Ave, Cincinnati, 45229, OH, USA
[b] Division of Pulmonary Medicine, Cincinnati Children's Hospital Medical Center, 3333 Burnet Ave, Cincinnati, 45229, OH, USA
[c] Division of Behavioral Medicine and Clinical Psychology, Cincinnati Children's Hospital Medical Center, 3333 Burnet Ave, Cincinnati, 45229, OH, USA
[d] Department of Otolaryngology, University of Cincinnati, College of Medicine, 231 Albert Sabin Way, Cincinnati, 45267, OH, USA
[e] Department of Pediatrics, Case Western Reserve University School of Medicine, 11100 Euclid Ave, Cleveland, 44106, OH, USA
[f] Division of Neonatology, University Hospitals Cleveland Medical Center Rainbow Babies and Children's Hospital, 11100 Euclid Ave, Cleveland, 44106, OH, USA

ARTICLE INFO

Keywords:
Ventilator
Tracheostomy
Education

ABSTRACT

Advances in neonatal care have led to increased survival of infants with complex medical needs and technology dependence. Transition of the ventilator-dependent infant from hospital to home is a complex process that requires extensive coordination between the medical team and family. Home caregivers must be prepared to provide routine care for the ventilator-dependent child and respond to life-threatening emergencies. Families should be counseled on the need for home nursing, medical equipment and an adequate home environment to ensure a safe transition to home. Throughout the process, the family may require financial, social and psychological support. A structured education and transition process that is clearly communicated to parents is necessary to have an effective partnership with families.

1. Introduction

Advances in the care of newborns with extreme prematurity or critical illness has led to increased survival of infants with chronic respiratory failure and complex medical conditions [1,2]. Infants with chronic respiratory failure requiring mechanical ventilation require extensive planning and coordination between inpatient care teams, home nursing agencies, durable medical equipment (DME) companies, outpatient medical teams, managed care plans and families to ensure a safe transition to home. The complexity of the discharge process can lead to prolonged time in the hospital, causing additional stress to the family [3]. Working with families to teach skills necessary to care for the ventilator-dependent child in the home and navigate the complexities of the medical system, while attending to the family's own needs, is critical to successful care outside the hospital.

Despite the complexity and high cost of care associated with children dependent on tracheostomy and home mechanical ventilation, there is little evidence to guide clinical practice. Several institutions have published single-center experiences describing the preparation of the family for home [4,5]. In 2016, the American Thoracic Society (ATS) published a set of clinical practice guidelines to assist clinicians in planning a safe transition to home for children with chronic invasive ventilation [6]. These guidelines include educational objectives regarding the necessary knowledge and skills recommended for family members trained to care for children requiring home mechanical ventilation.

2. Counseling prior to tracheostomy

Preparing families to care for a ventilated infant at home begins prior to tracheostomy. Families should be counseled on the expected duration of mechanical ventilation and need for tracheostomy depending on the underlying reason for chronic respiratory failure, as well as the uncertainty in predicting these timelines. Implications of long-term ventilation should also be discussed with families, including both benefits and risks to the child and families who provide care at home. While there are clear benefits to the child, including enhanced psychosocial development and social integration, care at home does not come without risks [7]. Even with home monitoring and nursing support, infants are at risk for catastrophic events related to accidental decannulation or mechanical obstruction of the tracheostomy tube [8,9]. Because of the risk for a catastrophic event, the ATS guidelines strongly recommended an awake and trained caregiver attend to the child at all times [6].

Families may also be impacted by the burden of caring for a child with complex medical needs resulting in stress, sleep deprivation and

---

[*] Corresponding author. Department of Pediatrics, University of Cincinnati, College of Medicine, 3333 Burnet Ave, Cincinnati, 45229, OH, USA.
E-mail addresses: Dan.benscoter@cchmc.org (D. Benscoter), Adrienne.borschuk@cchmc.org (A. Borschuk), Catherine.hart@cchmc.org (C. Hart), kcvoos@yahoo.com (K. Voos).

https://doi.org/10.1016/j.siny.2019.101042

fatigue impacting relationships with family members and friends [10]. Family members may also make sacrifices to careers due to the critical shortage of home nurses to provide care for children in the home. This may result in financial loss or dissatisfaction with leaving a burgeoning career [11]. Many parents feel a sense of isolation and may struggle to create common routines to feel a sense of normalcy [12,13]. While most families state that these realities do not factor into the decision to pursue tracheostomy and long-term ventilation for the child, parents should be counseled on the impact on relationships, including those with other children in the home, especially when the child's underlying disease predicts that home ventilation will be lifelong with liberation from ventilation and decannulation as unlikely outcomes.

The process of transitioning to home should also be discussed with families prior to tracheostomy. Parents should have an understanding of the expectations from the medical team, including requirements for number of trained caregivers, education timelines and need for overnight stays if required. Most centers require at least two fully trained and committed caregivers. Potential barriers to discharge, including acquisition of home nursing and medical equipment, insurance approval and requirements for the home, should be made clear to families to foster family and medical team partnership and keep all parties on the same page. The process to transition to home can be long and stressful for families and setting clear expectations early will benefit parents and the medical team.

3. Partnering with families

Best practices in helping families and young children in the transition from the hospital NICU to home include optimizing early caregiver involvement in an infant's care, shared decision making, preparing the home environment for the technology-dependent child, preparing an appropriate discharge plan, using a standardized team based approach and identifying community resources [14–27]. It takes time for the family of a high-risk infant to prepare to care for their infant at home and to secure the necessary support services and community resources.

The principles of family-centered, family integrated neonatal care clearly promote family participation in every aspect of their infant's care. Most of the foundational work of family-centered care rests on effective communication [28,29]. It is well-established that specific health care provider and patient/parent communication behaviors are associated with improved patient health status, recall, treatment adherence, and satisfaction [29,30]. The role of the health care professionals in communicating medical information is important. Parents need a realistic assessment of the situation that is honest and direct. Many parents desire and can handle complete, specific, honest, detailed, unbiased, and meaningful information—the same facts and interpretation of those facts as the staff—delivered in a humane and respectful manner [31].

There are several other guidelines in communicating medical information to parents. As discussed, parents' perceptions of their infant's condition are extremely important, remain in parents' minds, and can affect their relationship with the infant. It is essential to determine and address their perceptions. A team member might specifically ask about the parents' concerns or worries: “Could you tell me what concerns you have about taking your baby home?” During the course of preparing for discharge, it is useful to determine parents' interpretations of what has been said and modify and clarify as needed. It is more productive to move at a pace that allows the parent to assimilate the information presented. It is important to use simple language that is understandable. Preforming a parent learning assessment or asking “How they learn best?” can assist the team in enhancing the families' ability to retain information needed to take an infant home with complex needs. Use of pictures or instructional videos can augment what is being explained. Providing a list of common medical terms and educational materials in the native language of the parents is a useful tool.

At times, despite numerous discussions about the infant's medical condition, the family may appear unable to comprehend what they have been told. Poor understanding by parents may be the result of poor communication techniques, contradictory messages, poor parental health, inexperience with medical terminology, denial, language barriers, inability to ask questions, or lack of opportunity to review the information. In one study, parents claimed that a neonatologist had never spoken to them, but, in fact, the conversation did occur and had been recorded [30]. Consider that even if the health care provider and family share the same language, the words may have different meanings depending on core cultural beliefs and values and the families' previous experiences. If a specialist physician and the NICU team are both communicating with the parents, it is essential to coordinate the particular approach. It is very confusing to parents and decreases their trust level if they receive conflicting information.

Parents must feel a sense of competency in relating to and caring for their infant. Discharge is an anxiety-provoking event and ushers in the “crisis” of homecoming, which parents must face and master [32–34]. The perinatal health care team can employ many interventions to assist parents with discharge. In the hospital, adequate teaching of caregiving skills that enable the parent to develop a sense of mastery and competence is important. Care by parents before discharge enables parents to assume full responsibility for their infant's care, tests the reality of caregiving, helps them learn caregiving activities and their infant's behavioral patterns, and confirms their readiness for independent parenting and the infant's readiness for discharge [17,18,35].

Parent education regarding the care and needs of their baby is a learning process that begins at admission and continues throughout the inpatient stay. Journey boards may provide a road map for families to track progress throughout the discharge process [5]. In addition to learning skills, parents need to be able to recognize signs and symptoms of illness and respond appropriately, especially in emergency situations [20–23,27]. Providing families with tools for recognition, such as a red flag action plan, can be helpful. In addition to tasks of care, parents should participate in planning and providing developmentally appropriate care and be able to read and respond to their infant's cues.

4. Psychological support for families

Psychological literature related to infants with tracheostomy and ventilator dependence is sparse; however, research indicates that caregivers of children requiring mechanical ventilation are at high risk of developing symptoms of trauma, anxiety, and depression [36,37]. Stressors inherent in the care environment, chronicity of admissions, and the intense coordination required to facilitate discharge home place families and patients at risk for long-term psychological distress and sub-optimal outcomes.

Caregivers of mechanically ventilated children stand to benefit from acute and chronic psychological support while in the hospital [38,39]. It is standard practice in other chronic care populations (e.g., cystic fibrosis), to screen caregivers for symptoms of anxiety and depression [40]. Use of a brief, broad-based psychological screener (e.g., NIH Toolbox Perceived Stress) is recommended to identify, triage, and treat mental health needs [41]. Suggested acute inpatient interventions include support around acute medical events, decision-making, and family/provider meetings [42]. For ongoing treatment, evidence-based options include cognitive-behavioral therapy (CBT), trauma-focused CBT, acceptance and commitment therapy, problem-solving therapy, and interpersonal therapy [43–47]. Given that the transition to home is a notably stressful time, psychological support should be provided through the end of the family's admission, with clear resources identified and referrals provided in their community to continue treatment. Ideally, skills learned by families during their child's hospitalization will contribute to a safe and positive transition home, and promote healthy coping over the long term.

5. Educating families

Education for home caregivers is critical to a safe transition to home. The ATS has developed guidelines on the care of children with a tracheostomy and home ventilator that emphasize the importance of educating home caregivers on routine care and emergency management for the ventilator-dependent child [6]. As adult learners, parents should be involved in planning their education [48]. Assessment of the parent's preferred learning style should be performed early in the education process and repeated at intervals to ensure that the educational program is effective. Teaching methods may include verbal or written instruction, demonstration, active participation, audio or visual materials. Ideally, the education curriculum utilizes a variety of teaching methods [21]. Families should have the ability to "teach back" skills learned during the education process [49]. The education process includes mastery of specific skills and understanding management of problems that may occur at home. Education should be performed by staff comfortable with teaching skills, correcting mistakes and answering caregiver's questions. Ideally, staff is involved in educating families frequently to maintain this specific skill set. A structured education process may result in reduced length of stay [5,50].

Prior to transition to home, parents should be proficient in managing the tracheostomy tube, home ventilator, oxygen delivery and airway clearance devices if indicated, as well as feeding and medication administration. Parents must also be able to obtain and understand the importance of routine vital signs. Instruction should be provided on the use and interpretation of the home oximeter. Caregivers should also have the ability to incorporate these skills during an in-hospital stay with the infant when the caregiver is responsible for providing all care to be performed at home while in the hospital room. Once fully trained, family members may have a similar understanding of how to respond to emergencies when compared to trained nurses [51].

5.1. Tracheostomy education

Early and ongoing education focused on routine and emergency care for the infant's tracheostomy tube should start prior to tracheostomy. Parents can practice skills on a model prior to providing care to the child. Tracheostomy skills should be reinforced throughout the hospitalization by providing routine care once parents are comfortable with skills. Skills should include suctioning, stoma care, tracheostomy tie changes and tracheostomy tube changes [6]. Tracheostomy tube changes should be mastered using two caregivers and with only one caregiver in the event that an emergent tube change is required when only one parent is present. Families should be provided a self-inflating bag and should be proficient in its use. If the child uses a cuffed tracheostomy tube, instruction should be provided on how and when to inflate the cuff.

In addition to skills, families should also receive comprehensive education on medical management of a tracheostomy as well as symptom recognition [52]. Education should include a description of normal and abnormal secretions, signs of skin infection and causes of bleeding from and around the tracheostomy tube and stoma. Families should understand risk factors for accidental decannulation and mucus plugging and demonstrate appropriate tracheostomy tie assessment and use of humidification. Families should also describe signs of respiratory distress and discuss scenarios when they may be required to manage bronchospasm, mucus plugging, bleeding or accidental decannulation. In the event that a tracheostomy tube cannot be easily replaced, families must know where a back-up tube is located and be prepared to place a smaller tracheostomy tube if necessary. Families must be instructed to keep a supply bag including back-up tracheostomy tubes with the patient at all times [53]. Understanding whether the infant can successfully receive manual bag ventilation using a facemask or be endotracheally intubated in the event of an emergency could be lifesaving if a tube cannot be easily passed through the stoma.

5.2. Ventilator education

Ventilator equipment and ventilator settings are complex and should be distilled when educating families. Parents must be able to turn the ventilator on and off and should be able to efficiently take the infant off ventilator support to allow for safe transport in and out of the bed or vehicle [6]. Instruction should be provided on assembly of the ventilator circuit and humidifier. Parents should be comfortable adding supplemental oxygen to the circuit or directly to the tracheostomy tube as indicated. Caregivers should have a basic understanding of their child's mode of ventilation and settings. While most physicians do not advocate for a home caregiver to unilaterally change ventilator settings, parents should be able to recognize correct and incorrect settings in the event that the prescribed ventilator settings are inadvertently changed. Although parents should not be expected to recite the child's ventilator mode and settings, correct settings should be available to be readily referenced.

Families should also receive education on troubleshooting problems with the ventilator in the home [52]. Parents should be comfortable with steps to take in the event of a power outage in the home, including use of a reserve fully-charged battery and ability to use a self-inflating bag if needed while calling the electric company and seeking medical attention as necessary. Families should also be counseled on the meaning of and actions to take in response to various home ventilator alarms. Ventilator alarms should not be silenced or discontinued by family members. The limitations of home ventilator alarms should be emphasized with families frequently. It should be made clear that alarms can fail and are not a substitute for the watchful eye of an awake and trained caregiver [54]. The need for an awake and trained caregiver watching the child at all times is critical to prevent death or neurologic disability due to accidental decannulation, ventilator circuit disconnect or tracheostomy tube obstruction [6].

5.3. In-hospital stay

After families have completed education on individual skills, caregivers should be offered the opportunity to room-in with the child during an in-hospital stay [4]. The duration of the in-hospital stay varies among centers, though most will offer at least a 24-h stay. During this time, the infant remains under supervision of the hospital staff and medical team; however, the caregiver is expected to provide all care that will be provided in the home including tracheostomy care and medication and feed administration. Caregivers are also expected to respond appropriately to the child's cues and ventilator alarms. Expectations for family members during the in-hospital stay should be clear and provided in advance with an understanding that the caregiver may be asked to repeat the stay should concerns arise during the in-hospital stay.

5.4. Simulation

Recently the utility of high-fidelity simulation to augment parent education has been studied. Simulating scenarios that may be encountered in the home may improve parental confidence in managing the child and responding to emergencies in the home, especially when focused on events unlikely to occur or be managed by the parents in the hospital setting [55]. All families should learn cardiopulmonary resuscitation (CPR), which can be incorporated into high-fidelity simulation. Any use of high-fidelity simulation should be accompanied by a debriefing session with the caregivers to discuss specific learning points. Use of simulation training with families prior to transition to home led to a reduction in the risk of readmission within seven days of discharge at one center [56]. Significant barriers to including high-fidelity simulation into family education programs include the cost of high-fidelity manikins and the time required of staff to become familiar with the manikin, develop scenarios and run the simulation with family members.

6. Guidance on home environment readiness

Discussion of the appropriateness of the home environment should be introduced with families early in the process. Some families may have difficulty discussing the home environment or making necessary changes. The hospital social worker can support families through this process and connect families to available resources in the community. The DME company will inspect the home prior to the child transitioning to the home environment. Prior to this visit, families should understand the need for adequate power supply and safe and grounded electrical outlets, smoke detectors, carbon monoxide detectors and fire extinguishers [7]. While some deficiencies can be easily corrected, it would behoove a family to address needed electrical work or construction early to avoid delays in discharge. With a large amount of equipment needed to care for a ventilator-dependent child, the bedroom should be of sufficient size to contain all necessary equipment. Families without sufficient space or those living on higher level floors requiring transport of the child and equipment up several flights of stairs may consider moving to another home or apartment. The general cleanliness and organization of the home should also be considered so as not to impair the ability to care for the child. Additionally, families should be counseled on smoking cessation if applicable. Direct and even second-hand tobacco smoke exposure can adversely affect the ventilator-dependent child once in the home. If oxygen tanks are in the home, signs should be placed to alert family members and visitors to the danger of smoking in the home.

7. Guidance on finding home nursing support and medical equipment

There is a critical shortage of home nurses able to care for a child with a home ventilator in most communities [57,58]. Families should be counseled on the difficulty in finding home nursing early in the process. It is not uncommon for the infant to be medically stable with all family education completed and discharge to be delayed due to an inability to find home nursing. Families should also have an understanding of the importance of home nursing in most situations to ensure that there is an awake and trained caregiver watching the child at all times. The medical team and social worker will work with local home nursing agencies to identify home nurses. In our experience, many families have had greater success using social media or working through local community groups or churches to find home nurses. Families should be encouraged to utilize all resources available in the search for home nurses, including asking friends and family members whether they know nurses interested in providing care in the home. The search for home nursing should be initiated early and families should be encouraged to be proactive in this process [5].

Families should also be aware that home nurses will be trained by the home nursing agency but may not have the opportunity to meet their child until he or she is in the home. While the home nurse will have specific orders for medications, feeds and treatments, families will be responsible for teaching the new home nurse about care preferences and their child's response to the way care is provided. Parents should be prepared to ask prospective home nurses about their experience with children with chronic medical needs; however, even home nurses with extensive experience will need time to learn the specific needs of each new patient. Families should also be aware that even if home nursing is secured, there may be days or nights when a home nurse is unavailable to be present in the home due to illness or family emergency [7].

Likewise, families should have an understanding of the vast number of supplies and medical equipment needed in the home. Identification of a DME company should occur early in the process to ensure that approval and procurement of equipment does not delay the transition to home. Parents should have the opportunity to see examples of equipment and supplies that are well-organized in the home. Families without an organization plan may be overwhelmed by a large number of supplies at home and should understand that difficulty in locating supplies can impact the child's care. Caregivers should be taught to recognize signs of equipment malfunction and should have the phone number for the DME company readily available to assist in troubleshooting and replacement of equipment as necessary.

8. Guidance on financial resources

Families may experience tremendous financial hardship during the child's hospitalization and following transition to home [13]. A parent is often forced to stop working to stay home with a ventilator-dependent child as 24-h home nursing is rarely available. In addition to the loss of income, home modifications, cost of supplies and frequent appointments increase financial pressure on the family. Early in the hospitalization, a social worker and financial assistant should work with the family to assess the current insurance plan and apply for Medicaid services or a Medicaid waiver program depending on the state of residence [7]. These financial barriers will need to be addressed prior to securing home medical equipment and home nursing. Prior to transitioning home, families should be given contact information for resources in the community including cash, food or utility assistance programs if indicated and available in the community.

9. Preparing the family for medical care in the community

The medical team should help families create connections with healthcare professionals in the community. Families should be counseled to choose a general pediatrician comfortable caring for a child with a tracheostomy tube and home ventilator, even if this means going to a different pediatrician from whom a sibling is established. A conference call should be arranged with the accepting pediatrician to discuss the child's medical needs, preferably with the family present. Many infants with technology dependence require care with multiple subspecialists and contact information should be provided with clear instructions as to which office to call depending on the infant's needs. A similar hand-off should be performed if an infant is to attend a medical daycare if this is available in the area.

Families should also be connected to local emergency medical services (EMS), specifically the agency that would respond to the home in the event of an emergency. A home visit with EMS personnel can be very beneficial, allowing EMS to survey the home for potential barriers to providing emergency care. A home visit with EMS also allows first responders to meet the child and family and become familiar with the home. In our experience, the EMS home visit has increased family confidence as parents have the opportunity to display their own knowledge and skills to first responders, many of whom have little or no experience with pediatric tracheostomy tubes or home ventilators.

An emergency plan should be prepared and discussed with families detailing actions in the event of a change in the child's condition [7]. Emergency plans may be used to guide caregiver responses for respiratory distress, desaturations, accidental decannulation, tracheostomy bleeding and other changes in the infant's status. Phone numbers to contact members of the outpatient medical team should be included when symptoms are mild and instructions to call EMS should be included when symptoms are more severe. If an emergency plan is developed, it should be shared with the outpatient medical team and EMS.

10. Going home

As the anticipated date to transition home nears, families should have the opportunity to meet with the entire inpatient care team together. At this time, the discharge plan should be reviewed and families should have the opportunity to ask any lingering questions. This is an opportune time to include the accepting outpatient pediatrician as well as any relevant subspecialists who are able to attend. Ideally, a representative from the home nursing agency and DME company would also be present to review the discharge plan and answer questions to ensure that families receive a clear and consistent message on all aspects of care.

11. Conclusion

Hospitalization of the infant dependent on invasive ventilation is long and stressful to families. The discharge process is equally complex and requires a close partnership between the family and the medical team. Great care should be taken to provide clear and consistent communication with the family and to allow caregivers to assume increasing responsibility throughout the hospital stay. Though it will be natural for families to have anxiety about the transition to home, an effective education program and guidance throughout the discharge process will prepare families to safely care for the ventilator-dependent infant in the home.

Practice points

- Little evidence exists to guide clinical practice.
- Clear and consistent communication with families is necessary throughout the transition process.
- Standardized discharge processes may reduce length of stay.
- Use of high-fidelity simulation may improve parent confidence in emergency situations.
- Families must be aware of the need for an awake and trained caregiver with the child at all times.

Declaration of competing interest

The authors have no financial or personal relationships that would inappropriately influence the content of this article.

References

[1] Simon TD, Berry J, Feudtner C, Stone BL, Sheng X, Bratton SL, et al. Children with complex chronic conditions in inpatient hospital settings in the United States. Pediatrics 2010;126(4):647–55.
[2] Amin R, Sayal P, Syed F, Chaves A, Moraes TJ, MacLusky I. Pediatric long-term home mechanical ventilation: twenty years of follow-up from one Canadian center. Pediatr Pulmonol 2014;49(8):816–24.
[3] Edwards EA, O'Toole M, Wallis C. Sending children home on tracheostomy dependent ventilation: pitfalls and outcomes. Arch Dis Child 2004;89(3):251–5.
[4] Baker CD. Long-term ventilation for children with chronic lung disease of infancy. Curr Opin Pediatr 2019;31:357–66.
[5] Baker CD, Martin S, Thrasher J, et al. A standardized discharge process decreases length of stay for ventilator-dependent children. Pediatrics 2016;137(4):e20150637.
[6] Sterni LM, Collaco JM, Baker CD, Carroll JL, Sharma GD, Brozek JL, et al. An official American Thoracic Society clinical practice guideline: pediatric chronic home invasive ventilation. Am J Respir Crit Care Med 2016;193(8). e15–35.
[7] Barnhart S, Carpenter A. Transition from hospital to home. In: Sterni LM, Carroll JL, editors. Caring for the ventilator dependent child: a clinical guide. Humana Press; 2016. p. 89–119.
[8] Edwards JD, Kun SS, Keens TG. Outcomes and causes of death in children on home mechanical ventilation via trachesotomy: an institutional and literature review. J Pediatr 2010;157(6):955–9.
[9] Boroughs D, Dougherty JA. Decreasing accidental mortality of ventilator-dependent children at home: a call to action. Home Healthc Nurse 2012;30(2):103–11.
[10] Meltzer LJ, Boroughs DS, Downes JJ. The relationship between home nursing coverage, sleep, and daytime functioning in parents of ventilator-assisted children. J Pediatr Nurs 2010;25(4):250–7.
[11] Hefner JL, Tsai WC. Ventilator-dependent children and the health services system. Unmet needs and coordination of care. Ann Tm Thorac Soc 2013;10(5):482–9.
[12] Graham RJ, Pemstein DM, Palfrey JS. Included but isolated: early intervention programmes provision for children and families with chronic respiratory support needs. Child Care Health Dev 2018;34(3):373–9.
[13] Carnevale FA, Alexander E, Davis M, Rennick J, Troini R. Daily living with distress and enrichment: the moral experience of families with ventilator-assisted children at home. Pediatrics 2006;117(1). e48–60.
[14] Huning BM, Reimann M, Beerenberg U, Stein A, Schmidt A, Felderhoff-Muser U. Establishment of a family-centred care programme with follow-up home visits: implications for clinical care and economic characteristics. Klin Pädiatr 2012;224(7):431–6.
[15] Johnston AM, Bullock CE, Graham JE, et al. Implementation and case-study results of potentially better practices for family-centered care: the family-centered care map. Pediatrics 2006;118(Suppl 2):S108–14.
[16] Broedsgaard A, Wagner L. How to facilitate parents and their premature infant for the transition home. Int Nurs Rev 2005;52(3):196–203.
[17] Melnyk BM, Feinstein NF, Alpert-Gillis L, et al. Reducing premature infants' length of stay and improving parents' mental health outcomes with the Creating Opportunities for Parent Empowerment (COPE) neonatal intensive care unit program: a randomized, controlled trial. Pediatrics 2006;118(5). e1414–1427.
[18] Bracht M, O'Leary L, Lee SK, O'Brien K. Implementing family-integrated care in the NICU: a parent education and support program. Adv Neonatal Care 2013;13(2):115–26.
[19] Joseph RA. Tracheostomy in infants: parent education for home care. Neonatal Netw 2011;30(4):231–42.
[20] Forsythe PL, Maher R, Kirchick C, Bieda A. SAFE discharge for infants with high-risk home environments. Adv Neonatal Care 2007;7(2):69–75.
[21] Griffin T, Abraham M. Transition to home from the newborn intensive care unit: applying the principles of family-centered care to the discharge process. J Perinat Neonatal Nurs 2006;20(3):243–9.
[22] Jefferies AL. Canadian paediatric society, fetus and newborn committee. Going home: facilitating discharge of the preterm infant. Paediatr Child Health 2014;19(1):31–42.
[23] Schlittenhart JM, Smart D, Miller K, Severtson B. Preparing parents for NICU discharge: an evidence-based teaching tool. Nurs Womens Health 2011;15(6):484–94.
[24] Willis V. Parenting preemies: a unique program for family support and education after NICU discharge. Adv Neonatal Care 2008;8(4):221–30.
[25] Sims DC, Jacob J, Mills MM, Fett PA, Novak G. Evaluation and development of potentially better practices to improve the discharge process in the neonatal intensive care unit. Pediatrics 2006;118(Suppl 2):S115–23.
[26] Mills MM, Sims DC, Jacob J. Implementation and case-study results of potentially better practices to improve the discharge process in the neonatal intensive care unit. Pediatrics 2006;118(Suppl 2):S124–33.
[27] American Academy of Pediatrics Committee on Fetus and Newborn. Hospital discharge of the high-risk neonate. Pediatrics 2008;122(5):1119–26.
[28] Stein T, Frankel RM, Krupat E. Enhancing clinician communication skills in a large healthcare organization: a longitudinal case study. Patient Educ Couns 2005;58(1):4–12.
[29] Kaplan SH, Greenfield S, Ware Jr. JE. Assessing the effects of physician-patient interactions on the outcomes of chronic disease. Med Care 1989;27:110–27.
[30] Koh TH, Jarvis C. Promoting effective communication in neonatal intensive care units by audiotaping doctor- parent conversations. Int J Clin Pract 1998;52(1):27–9.
[31] Harrison H. The principles for family-centered neonatal care. Pediatrics 1993;92(5):643–50.
[32] Thomas KA, Renaud MT, DePaul D. Use of the parenting stress index in mothers of preterm infants. Adv Neonatal Care 2004;4:33–41.
[33] Lundqvist P, Jakobsson L. Swedish men's experiences of becoming fathers to their preterm infants. Neonatal Netw 2003;22(6):25–31.
[34] Jackson K, Ternestedt BM, Schollin J. From alienation to familiarity: experiences of mothers and fathers of preterm infants. J Adv Nurs 2003;43:120–9.
[35] Hummel P. Parenting in the high-risk infant. Newborn Infant Nurs Rev 2003;3:88–92.
[36] Toly VB, Musil CM, Carl JC. Families with children who are technology dependent: normalization and family functioning. West J Nurs Res 2012;34(1):52–71.
[37] Vanderbilt D, Bushley T, Young R, Frank DA. Acute posttraumatic stress symptoms among urban mothers with newborns in the neonatal intensive care unit: a preliminary study. J Dev Behav Pediatr 2009;30(1):50–6.
[38] Chan YH, Lim CZ, Bautista D, Malhotra R, Ostbye T. The health and well-being of caregivers of technologically dependent children. Glob Pediatr Health 2019;6:1–11.
[39] Sweeney D, Paliga JT, Reid RR, Shay PL, Goldstein JA, Bartlett SP, et al. The impact of a parent liaison at a major craniofacial center. J Craniofac Surg 2013;24(6):1898–901.
[40] Quittner AL, Abbott J, Georgiopoulos AM, Goldbeck L, Smith B, Hempstead SE, et al. International committee on mental health in cystic fibrosis: cystic fibrosis foundation and European cystic fibrosis society consensus statements for screening and treating depression and anxiety. Thorax 2016;71(1):26–34.
[41] Gershon RC, Wagster MV, Hendrie HC, Fox NA, Cook KF, Nowinski CJ. NIH toolbox for assessment of neurological and behavioral function. Neurology 2013;80(11 Suppl 3):S2–6.
[42] Doupnik SK, Hill D, Palakshappa D, Worsley D, Bae H, Shaik A, et al. Parent coping support interventions during acute pediatric hospitalizations: a meta-analysis. Pediatrics 2017;140(3):e20164171.
[43] Chong YY, Mak YW, Leung SP, Lam SY, Loke AY. Acceptance and commitment therapy for parental management of childhood asthma: an RCT. Pediatrics 2019;143(2):e20191723.
[44] Eccleston C, Fisher E, Law E, Bartlett J, Palermo TM. Psychological interventions for parents of children and adolescents with chronic illness. Cochrane Database Syst Rev 2015;4:CD009660.
[45] Whittingham K, Sanders MR, McKinlay L, Boyd RN. Parenting intervention combined with acceptance and commitment therapy: a trial with families of children with cerebral palsy. J Pediatr Psychol 2016;41(5):531–42.
[46] Shaw RJ, St John N, Lilo E, Jo B, Benitz W, Stevenson DK, et al. Prevention of traumatic stress in mothers of preterms: 6-month outcomes. Pediatrics 2014;134(2).

e481–488.

[47] Handley ED, Michl-Petzing LC, Rogosch FA, Cicchetti D, Toth SL. Developmental cascade effects of interpersonal psychotherapy for depressed mothers: longitudinal associations with toddler attachment, temperament, and maternal parenting efficacy. Dev Psychopathol 2017;29(2):601–15.

[48] Knowles MS. Andragogy in action. Jossey-Bass; 1984.

[49] Kornburger C, Gibson C, Sadowski S, Maletta K, Klingbeil C. Using 'teach-back' to promote a safe transition from hospital to home: an evidence-based approach to improving the discharge process. J Pediatr Nurs 2013;28(3):282–91.

[50] Graf JM, Montagnino Hueckel R, Mcpherson ML. Children with new tracheostomies: planning for family education and common impediments to discharge. Pediatr Pulmonol 2008;43(8):788–94.

[51] Kun SS, Davidson-Ward SL, Hulse LM, Keens TG. How much do primary care givers know about tracheostomy and home ventilator emergency care? Pediatr Pulmonol 2010;45(3):270–4.

[52] Amin R, Parshuram C, Kelso J, Lim A, Mateos D, Mitchell I, et al. Caregiver knowledge and skills to safely care for pediatric tracheostomy ventilation at home. Pediatr Pulmonol 2017;52(12):1610–5.

[53] Amin R, Zabih W, Syed F, Polyviou J, Tran T, Propst EJ, et al. What families have in the emergency tracheostomy kits: identifying gaps to improve patient safety. Pediatr Pulmonol 2017;52(12):1605–9.

[54] Kun SS, Nakamura CT, Ripka JF, Davidson Ward SL, Keens TG. Home ventilator low-pressure alarms fail to detect accidental decannulation with pediatric tracheostomy tubes. Chest 2001;119(2):562–654.

[55] Tofil NM, Rutledge C, Zinkan JL, Youngblood AQ, Stone J, Peterson DT, et al. Ventilator caregiver education through the use of high-fidelity pediatric simulators: a pilot study. Clin Pediatr 2013;52(11):1038–43.

[56] Thrasher J, Baker J, Ventre KM, et al. Hospital to home: a quality improvement initiative to implement high-fidelity simulation training for caregivers of children requiring long-term mechanical ventilation. J Pediatr Nurs 2018;38:114–21.

[57] Sobotka SA, Gaur DS, Goodman DM, Agrawal RK, Berry JG, Graham RJ. Pediatric patients with home mechanical ventilation: the health services landscape. Pediatr Pulmonol 2019;54:40–6.

[58] Maynard R, Christensen E, Cady R, Jacob A, Ouellette Y, Podgorski H, et al. Home health care availability and discharge delays in children with medical complexity. Pediatrics 2019;143(1):e20181951.