Aiding Difficult and High-Stakes Medical Decision Making—Research on Parental Tracheostomy Decisions for Critically Ill Children

by

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Dedication

To my mom and dad, my first research mentors, my music teachers, who inspired and supported difficult and high-stakes decisions in my life.

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Abstract

This dissertation illustrated the multiple approaches necessary to improving decision making in applied settings. It consists of three studies that aimed to understand high-stakes pediatric tracheostomy decisions and aid parents' abilities to make these decisions. Chapter 1 involved an interview study of parents who had recently made a tracheostomy decision for their critically ill child. We found that parents were stressed and worried about future outcomes. They sought and desired information and emotional support for making this difficult decision. Despite these efforts, there seemed to exist opportunities to improve their understanding and forecasting of long-term challenges of a tracheostomy placement. Based on the literature of forecasting errors and narrative-form communication, Chapter 2 involved a survey experiment to test a possible intervention approach. It showed that narratives describing challenges that affect the child's and/or the family's quality of life from the point of view of parents who had already experienced them reduced parents' tendency to choose tracheostomy. The effect was particularly strong when the narratives focused on challenges in the child's quality of life. These narratives also led to less optimistic forecasting. Based on findings from Chapters 1 and 2, Chapter 3 presented a user-centered design process used to create education materials that were designed to help parents understand major challenges in life after a tracheostomy placement. This dissertation extends the literature on using narrative-form communication to help decision makers anticipate future experiences and reduce forecasting errors. It also demonstrates the multiple types of research needed to develop educational communication that is ready for implementation in clinical settings.

Introduction

Across the life span and a wide range of domains—education, career, relationships, health—we face situations where we have to make important decisions and the decision process may be overwhelming. More often than not, we worry about whether we have made the right decision and how we can do better in the future. One of the ultimate goals of behavioral decision science is improving decision making, especially in difficult and high-stakes real-life situations (Keren & Wu, 2015). To fulfill this aim, researchers must first identify problems in the decision process and then design, test, and develop decision aids to facilitate decision making.

This dissertation included three stand-alone studies (chapters) to illustrate a process of *improving decision making*, using tracheostomy decisions for critically ill children as a case study. When a child patient needs long-term use of mechanical ventilation, a tracheotomy or a tracheostomy placement—a surgical procedure to create an opening (called a tracheostomy) in the child's windpipe, which allows direct access to breathing support—is under consideration to provide a stable airway (Deutsch, 2010; Pratt et al., 2008). In situations where the benefits and risks of pursuing a tracheostomy placement are not clear, parents make this decision for their child. Yet, this decision is difficult on many levels. Furthermore, many parents end up making this decision through a decision process that has substantial room for improvement.

This introduction to the dissertation reviews literature on characteristics of hard decisions, justifies the pediatric tracheostomy decision as a hard decision, and summarizes the content in the three chapters.

Tracheostomy Decisions for Critically Ill Children

Tracheostomy and mechanical ventilation have become popular life-sustaining techniques. In the past decades, the indications and implications of tracheostomy have changed from assisting acute episodes to managing chronic critical conditions that need prolonged mechanical ventilation. More and more tracheostomy placements have been performed on critically ill children (Gergin et al., 2016; Lewis et al., 2003; Yaneza et al., 2015), although its burden and benefits have been debated (Hebert et al., 2017; McPherson et al., 2017). When there is no clear evidence of how benefits and burden weigh against each other, parents are asked to consider whether or not to have their child receive a tracheostomy. This kind of pediatric tracheostomy decisions manifests all characteristics of a hard decision according to the definitions provided in Yates et al. (2003).

To begin with, potential outcomes are serious. In general, a tracheostomy provides a stable airway for critically ill child patients who may need long-term mechanical ventilation (Nelson & Mahant, 2014). Not pursuing a tracheostomy placement may imply a shorter life for the child and death is an irreversible outcome. Parents may experience more regret over inaction (not pursuing tracheostomy) over action (pursuing tracheostomy) (Gilovich & Medvec, 1994). On the other hand, pursuing a tracheostomy placement requires sufficient resources and dedicated caregivers to support the child's care and development (Carnevale et al., 2006; Garrubba et al., 2009; Janvier et al., 2012; McCormick et al., 2015). In addition, options are usually limited for critically ill children and there is no clear "best" route—none of the options can satisfy all needs and are free from unwanted outcomes. However, parents are unlikely to have made a tracheostomy decision before, so they may not have adequate information and understanding of this decision's implications for the future to support their opinions and decisions (e.g., McCormick et al., 2015) and thus may experience high decisional conflict—"a state of uncertainty about which course of action to take" (O'Connor, 1995). What is more, it is difficult for doctors to predict future outcomes (Nageswaran, Hurst, et al., 2018; Rasmussen et al., 2016) and for anyone to predict the availability of social support, the potential for technology advances, and the impact of other significant life events, such as migration or divorce. The uncertainty in both knowledge and the future makes it hard for parents to choose whether to pursue a tracheostomy placement.

In many tracheostomy decisions, multiple care options are reasonable, and thus the decision relies more on the family's values. However, the task of exploring values associated with possible outcomes is difficult in itself. Renjilian et al. (2013) have demonstrated that parents' decision making was influenced by their perceived role and duty as parents. Being a good parent for a critically ill child consists of many different attributes (Feudtner et al., 2015; McGraw et al., 2012; October et al., 2014; Roscigno et al., 2012), but not all of them could be fulfilled with one particular option. Pursuing a tracheostomy placement may give the child more time, but it may also impose more suffering on the patient and contradict valuing quality of life. In addition, pediatric patients are not capable of making decisions on their own, so parents or legal guardians make decisions for them. Surrogate decision making involves tremendous stress and challenges. In particular, surrogate decision makers (parents) may not perceive themselves to be ready to make such difficult decisions or to be able to predict what is in the patient's best interest and of the highest value (Pochard et al., 2005; Tilden et al., 2001; Vig et al., 2007).

Furthermore, this decision has such high stakes that many people are involved. Doctors, nurses, social workers, family members, and other patients' families are all likely to be involved in some form. As a result, tracheostomy decisions are a perfect example of shared decision making (e.g., Nelson & Mahant, 2014), a process by which providers and patients discuss options and agree on a course of action (Charles et al., 1999). The decision process, which involves frequent provider-family discussions and deliberations as well as watchful waiting in the intensive care unit, is stressful and onerous. People possess different knowledge and experiences, which may yield different recommendations and conclusions (Needle et al., 2012). Research has also shown that physicians' interactions and communication with parents have room for improvement (Greenway et al., 2019; Van Cleave et al., 2014) and parents have their own preferences and values, which providers should consider when giving recommendations (Wilfond, 2014).

In summary, a pediatric tracheostomy decision is high-stakes and value-laden. The decision process tends to be stressful and onerous in terms of evaluating options and deciding between different opinions and considerations. It is hence a suitable real-life example to study and improve hard decision process. The remainder of the introduction summarizes the motivation, method, findings, and implications of each chapter.

Chapter 1

To the best of our knowledge, there is no research that describes parents' tracheostomy decision process in real time or shortly after they made the decision, except for one study that interviewed caregivers of children who received tracheostomy in the past five years (Nageswaran, Golden, et al., 2018). Although various factors regarding tracheostomy decisions have been studied, including medical conditions (e.g., diseases, timing, and complications) as well as clinicians' and surrogate decision makers' beliefs and preferences, there possibly exists an opportunity to gain a systematic understanding of parents' decision-making experiences and critical considerations. We hoped to learn what have gone well and what could be improved to inform subsequent efforts to aid decision making.

We conducted semi-structured interviews with parents who recently made a tracheostomy decision for their critically ill child. In order to learn about their decision process, we first developed interview questions based on the *Cardinal Issue Perspective* (Yates, 2003), a framework that represents a broad range of relevant issues in decision making. We supplemented the interview guide with other questions relevant to the context of tracheostomy decisions. For example, we asked participants to define their interpretations of quality of life and the child's best interest and to discuss their regret in terms of the information received and the final decision reached.

Data analysis revealed six major themes. First, parents desired and sought emotional support and information about tracheostomy's influences on their child's and family's life from peer parents and other resources (e.g., websites). Second, parents were stressed and coped through self-education, prayer, and seeking professional therapy. Third, parents were presented alternatives to tracheostomy but some did not perceive these as "real choices" and faced difficult tradeoffs. Fourth, parents resisted tracheostomy initially and gradually came to acceptance. Fifth, all parents considered quality of life, albeit different expectations. Many placed high value on their child's comfort, normalcy, and survival while worrying about skills and resources for home care and child's well-being. Lastly, religious beliefs played an important role in decision making.

From the major themes, one important takeaway is that since parents had many questions and different expectations regarding child's and family's quality of life, more information about how a tracheostomy impacts the future life of the child and family may help parents to make more informed decisions in this context.

Chapter 2

Chapter 1 and the literature revealed that parents may not fully grasp the big picture of what pursuing a tracheostomy placement means for their child's life and their role as caregivers at the time of decision making. Parents value informed decision making for their critically ill children (McCormick et al., 2015; Meyer, 2006; October et al., 2014). However, they often struggle to understand different options and hope that clinicians could provide relevant information for decision making (Allen, 2014). In particular, as physicians tend to focus on immediate and short-term outcomes rather than long-term challenges of tracheostomy (Hebert et al., 2017; Nelson et al., 2005), we theorized that parents needed more information about challenges in order to accurately anticipate the future and make informed choices. Providing such information to inform evaluation of options addresses two core cardinal decision issues in the *Cardinal Issue Perspective* (Yates, 2003)—*Possibilities* (what possible outcomes are) and *Judgment* (how likely these outcomes will happen). This is nontrivial to improving decision making in this context because the literature has shown that caregivers suffer from decreased quality of their sleep, relationships, social life, and work (Flynn et al., 2013; Hopkins et al., 2009; Thyen et al., 1999) and feel that their only option is to keep the child alive (Carnevale et al., 2006).

The psychology literature refers to misprediction, or unrealistic expectations of these experiences as *forecasting errors,* in the sense that future outcomes turn out to be surprising (better or worse) than expected. There are many ways that forecasting the future can go wrong. For instance, people could have inaccurate judgments of the likelihood, duration, intensity, and valence of future outcomes and feelings or simply be unaware of possible future outcomes

(Gilbert et al., 1998; Gilovich et al., 2002; Wilson & Gilbert, 2003, 2005). Forecasting errors are common in health decisions (Halpern & Arnold, 2008).

Upon identifying the problem that parents may lack an understanding of long-term challenges associated with tracheostomy, we selected *narratives* as the form of communicating the information. First, narratives have been shown to influence perceptions of risks, behavioral intention, and decisions (Bekker et al., 2013). In particular, experience narratives provide illustrations of life after treatment, which are effective at correcting forecasting errors by helping people understand future experience (Shaffer & Zikmund-Fisher, 2013). Second, clinicians sometimes use medical jargon, which patients and surrogate decision makers do not want—instead, they wanted "a more human perspective" (Allen, 2014; Braun et al., 2008; Hanson et al., 1997; McCormick & Conley, 1995; Meert et al., 2008). Narratives are more user-friendly than numbers (Wise et al., 2008).

Therefore, in the study presented in Chapter 2, we carefully constructed narratives about challenges affecting the child's and the family's long-term quality of life and tested whether these narratives improved forecasting and decisions via a survey experiment. The main finding was that both types of narratives decreased the tendency to choose tracheostomy. The narratives about baby's quality of life produced a larger effect than the ones about family's quality of life. Moreover, narratives led to less optimistic forecasting, which was associated with less interest in tracheostomy. This research demonstrates that narratives clarifying long-term implications of pursuing tracheostomy have the potential to influence forecasting and decisions and therefore to support decision making.

Chapter 3

We learned from Chapter 1 that parents desire to learn from peer parents about how a tracheostomy will affect both their life and their child's life and from Chapter 2 that narratives might be an effective way of improving decisions. Therefore, we sought to create education materials that incorporated peer parent narratives to help parents understand future life challenges for more informed decision making. To achieve this aim, we had to determine what types of future experiences parents would be interested in hearing and what/how many perspectives to present. However, as experts, we may not fully understand parents' perspectives to develop education materials based on parents' needs. Therefore, we turned to a user-centered design (UCD) process, a commonly-used and recommended approach in product development to maximize the product's value to the users (ISO , 2010). We expected to produce a final product that providers and parents can use in consultations for such high-stakes tracheostomy decisions.

We asked parents who had gone through tracheostomy decision making for their critically ill child to iteratively describe their information needs and provide feedback on the design and content of the education materials. There were two design phases. Phase 1 primarily focused on what to include, while Phase 2 emphasized calibration of the tone and content of the education materials.

Phase 1 revealed that parents acknowledged potential forecasting errors that we identified and wanted all the information to address them as soon as tracheostomy becomes an option. We learned that parents had diverse interpretations of quality of life than expected—while some valued survival and comfort in breathing, some thought about the child's experiences in the future. They wanted most information to focus on how a tracheostomy would influence their child rather than themselves. Parents also confirmed their lack of knowledge about practical challenges in home care, nursing, and family dynamics but argued that different families might face different challenges and that there existed ways to deal with certain challenges. These findings contributed to a prototype informational booklet with three major content sections: child's quality of life, home care, and practical challenges (impact on income, family dynamics, etc). After four iterative cycles of feedback collection and draft revision, we refined the tone and content of the booklet to emphasize individualized situations and personal choice throughout, raise awareness of the seriousness of the decision and the importance of caregiver health, present concrete illustrations of future experiences, and balance the challenges with acknowledgement of positive outcomes and advice. We identified from these parents more support group resources to be included in the booklet. We also learned that parents preferred to use the booklet with support from the care team rather than reading it alone.

The UCD process enabled our design team to acquire a direct understanding of users' (parents') needs and perspectives, which allowed us to include perspectives that we initially overlooked and tailor the education materials to meet their expectations. Meanwhile, the final booklet turned out to represent an emphasis on cardinal decision issues of *Possibilities* (possible future outcomes), *Judgment* (e.g., expected duration of tracheostomy, difficulties in home care), *Value* (e.g., how much parents value certain outcomes), *Tradeoffs* (e.g., quality versus length of life, child's needs versus caregivers' needs), *Acceptability* (e.g., whether other family members accept this decision), and *Implementation* (e.g., how to sustain home care), while touching upon the preliminary cardinal issues of *Need* (when to make a decision), *Mode* (whom to include in decision making and use of the booklet), and *Investment* (validation of material and emotional costs during decision making). Our approach may be applicable to other healthcare contexts where researchers aim to develop education materials to fulfill patients' and caregivers' need for understanding experiences of treatments.

Overall, this research aimed to understand and improve high-stakes parental tracheostomy decisions. It illustrated the process of using mixed methods to improve decision making in an applied context and extended the use of narrative-form communication to support informed decision making by reducing forecasting errors in high-stakes pediatric tracheostomy decision context. It has important implications for practicing informed shared decision making for difficult medical decisions.

References

Allen, K. A. (2014). Parental decision-making for medically complex infants and children: An integrated literature review. *International Journal of Nursing Studies*, *51*(9), 1289–1304. https://doi.org/10.1016/j.ijnurstu.2014.02.003

Bekker, H. L., Winterbottom, A. E., Butow, P., Dillard, A. J., Feldman-Stewart, D., Fowler, F. J., Jibaja-Weiss, M. L., Shaffer, V. A., & Volk, R. J. (2013). Do personal stories make patient decision aids more effective? A critical review of theory and evidence. *BMC Medical Informatics and Decision Making*, *13*(2), Article S9. https://doi.org/10.1186/1472-6947-13-S2-S9

Braun, U. K., Beyth, R. J., Ford, M. E., & McCullough, L. B. (2008). Voices of African American, Caucasian, and Hispanic surrogates on the burdens of end-of-life decision making. *Journal of General Internal Medicine*, *23*(3), 267–274. https://doi.org/10.1007/s11606-007-0487-7

Carnevale, F. A., Alexander, E., Davis, M., Rennick, J., & Troini, R. (2006). Daily living with distress and enrichment: The moral experience of families with ventilator-assisted children at home. *Pediatrics*, *117*(1), e48–e60. https://doi.org/10.1542/peds.2005-0789

Charles, C., Gafni, A., & Whelan, T. (1999). Decision-making in the physician-patient encounter: Revisiting the shared treatment decision-making model. *Social Science & Medicine*, *49*(5), 651–661. https://doi.org/10.1016/s0277-9536(99)00145-8

Deutsch, E. S. (2010). Tracheostomy: Pediatric considerations. *Respiratory Care*, *55*(8), 1082–1090.

Feudtner, C., Walter, J. K., Faerber, J. A., Hill, D. L., Carroll, K. W., Mollen, C. J., Miller, V. A., Morrison, W. E., Munson, D., Kang, T. I., & Hinds, P. S. (2015). Good-parent beliefs of parents of seriously ill children. *JAMA Pediatrics*, *169*(1), 39–47. https://doi.org/10.1001/jamapediatrics.2014.2341

Flynn, A. P., Carter, B., Bray, L., & Donne, A. J. (2013). Parents' experiences and views of caring for a child with a tracheostomy: A literature review. *International Journal of Pediatric Otorhinolaryngology*, *77*(10), 1630–1634. https://doi.org/10.1016/j.ijporl.2013.07.020

Garrubba, M., Turner, T., & Grieveson, C. (2009). Multidisciplinary care for tracheostomy patients: A systematic review. *Critical Care*, *13*(6), Article R177. https://doi.org/10.1186/cc8159

Gergin, O., Adil, E. A., Kawai, K., Watters, K., Moritz, E., & Rahbar, R. (2016). Indications of pediatric tracheostomy over the last 30 years: Has anything changed? *International Journal of Pediatric Otorhinolaryngology*, *87*, 144–147. https://doi.org/10.1016/j.ijporl.2016.06.018

Gilbert, D. T., Pinel, E. C., Wilson, T. D., Wheatley, T. P., & Blumberg, S. J. (1998). Immune neglect: A source of durability bias in affective forecasting. *Journal of Personality and Social Psychology*, *75*(3), 617–638. https://doi.org/10.1037/0022-3514.75.3.617

Gilovich, T., Griffin, D., & Kahneman, D. (Eds.). (2002). *Heuristics and biases: The psychology of intuitive judgment*. Cambridge University Press. https://doi.org/10.1017/CBO9780511808098

Gilovich, T., & Medvec, V. H. (1994). The temporal pattern to the experience of regret. *Journal of Personality and Social Psychology*, *67*(3), 357–365. https://doi.org/10.1037/0022-3514.67.3.357

Greenway, T. L., Rosenthal, M. S., Murtha, T. D., Kandil, S. B., Talento, D. L., & Couloures, K. G. (2019). Barriers to communication in a PICU: A qualitative investigation of family and provider perceptions. *Pediatric Critical Care Medicine*, *20*(9), e415–e422. https://doi.org/10.1097/PCC.0000000000002070

Halpern, J., & Arnold, R. M. (2008). Affective forecasting: An unrecognized challenge in making serious health decisions. *Journal of General Internal Medicine*, *23*(10), 1708–1712. https://doi.org/10.1007/s11606-008-0719-5

Hanson, L. C., Danis, M., & Garrett, J. (1997). What Is wrong with end-of-life care? Opinions of bereaved family members. *Journal of the American Geriatrics Society*, *45*(11), 1339–1344. https://doi.org/10.1111/j.1532-5415.1997.tb02933.x

Hebert, L. M., Watson, A. C., Madrigal, V., & October, T. W. (2017). Discussing benefits and risks of tracheostomy: What physicians actually say. *Pediatric Critical Care Medicine*, *18*(12), e592–e597. https://doi.org/10.1097/PCC.0000000000001341

Hopkins, C., Whetstone, S., Foster, T., Blaney, S., & Morrison, G. (2009). The impact of paediatric tracheostomy on both patient and parent. *International Journal of Pediatric Otorhinolaryngology*, *73*(1), 15–20. https://doi.org/10.1016/j.ijporl.2008.09.010

ISO (2010). 9241-210: Ergonomics of human-system interaction–Part 210: Human-centred design for interactive systems.

Janvier, A., Farlow, B., & Wilfond, B. S. (2012). The experience of families with children with trisomy 13 and 18 in social networks. *Pediatrics*, *130*(2), 293–298. https://doi.org/10.1542/peds.2012-0151

Keren, G., & Wu, G. (2015). A bird's-eye view of the history of judgment and decision making. In Keren, G., & Wu, G. (Eds.), *The Wiley Blackwell handbook of judgment and decision* *making* (1st ed., pp. 1–39). John Wiley & Sons, Ltd. https://doi.org/10.1002/9781118468333.ch1

Lewis, C. W., Carron, J. D., Perkins, J. A., Sie, K. C. Y., & Feudtner, C. (2003). Tracheotomy in pediatric patients: A national perspective. *Archives of Otolaryngology–Head & Neck Surgery*, *129*(5), 523–529. https://doi.org/10.1001/archotol.129.5.523

McCormick, M. E., Ward, E., Roberson, D. W., Shah, R. K., Stachler, R. J., & Brenner, M. J. (2015). Life after tracheostomy: Patient and family perspectives on teaching, transitions, and multidisciplinary teams. *Otolaryngology–Head and Neck Surgery*, *153*(6), 914–920. https://doi.org/10.1177/0194599815599525

McCormick, T. R., & Conley, B. J. (1995). Patients' perspectives on dying and on the care of dying patients. *Western Journal of Medicine*, *163*(3), 236–243.

McPherson, M. L., Shekerdemian, L., Goldsworthy, M., Minard, C. G., Nelson, C. S., Stein, F., & Graf, J. M. (2017). A decade of pediatric tracheostomies: Indications, outcomes, and long-term prognosis. *Pediatric Pulmonology*, *52*(7), 946–953. https://doi.org/10.1002/ppul.23657

McGraw, S. A., Truog, R. D., Solomon, M. Z., Cohen-Bearak, A., Sellers, D. E., & Meyer, E. C. (2012). "I was able to still be her mom" Parenting at end of life in the PICU. *Pediatric Critical Care Medicine*, *13*(6), e350–e356. https://doi.org/10.1097/PCC.0b013e31825b5607

Meert, K. L., Eggly, S., Pollack, M., Anand, K. J. S., Zimmerman, J., Carcillo, J., Newth, C. J. L., Dean, J. M., Willson, D. F., & Nicholson, C. (2008). Parents' perspectives on physician-parent communication near the time of a child's death in the pediatric intensive care unit. *Pediatric Critical Care Medicine*, *9*(1), 2–7. https://doi.org/10.1097/01.PCC.0000298644.13882.88

Meyer, E. C. (2006). Improving the quality of end-of-life care in the pediatric intensive care unit: Parents' priorities and recommendations. *Pediatrics*, *117*(3), 649–657. https://doi.org/10.1542/peds.2005-0144

Nageswaran, S., Golden, S. L., Gower, W. A., & King, N. M. P. (2018). Caregiver perceptions about their decision to pursue tracheostomy for children with medical complexity. *The Journal of Pediatrics*, *203*, 354–360.e1. https://doi.org/10.1016/j.jpeds.2018.07.045

Nageswaran, S., Hurst, A., & Radulovic, A. (2018). Unexpected survivors: Children with life-limiting conditions of uncertain prognosis. *American Journal of Hospice and Palliative Medicine*, *35*(4), 690–696. https://doi.org/10.1177/1049909117739852

Needle, J. S., Mularski, R. A., Nguyen, T., & Fromme, E. K. (2012). Influence of personal preferences for life-sustaining treatment on medical decision making among pediatric intensivists. *Critical Care Medicine*, *40*(8), 2464–2469. https://doi.org/10.1097/CCM.0b013e318255d85b

Nelson, J. E., Kinjo, K., Meier, D. E., Ahmad, K., & Morrison, R. S. (2005). When critical illness becomes chronic: Informational needs of patients and families. *Journal of Critical Care*, *20*(1), 79–89. https://doi.org/10.1016/j.jcrc.2004.11.003

Nelson, K. E., & Mahant, S. (2014). Shared decision-making about assistive technology for the child with severe neurologic impairment. *Pediatric Clinics of North America*, *61*(4), 641–652. https://doi.org/10.1016/j.pcl.2014.04.001

O'Connor, A. M. (1995). Validation of a Decisional Conflict Scale. *Medical Decision Making*, *15*(1), 25–30. https://doi.org/10.1177/0272989X9501500105

October, T. W., Fisher, K. R., Feudtner, C., & Hinds, P. S. (2014). The parent perspective: “Being a good parent” when making critical decisions in the PICU. *Pediatric Critical Care Medicine*, *15*(4), 291–298. https://doi.org/10.1097/PCC.0000000000000076

Pochard, F., Darmon, M., Fassier, T., Bollaert, P. E., Cheval, C., Coloigner, M., Merouani, A., Moulront, S., Pigne, E., Pingat, J., Zahar, J. R., Schlemmer, B., & Azoulay, É. (2005). Symptoms of anxiety and depression in family members of intensive care unit patients before discharge or death. A prospective multicenter study. *Journal of Critical Care*, *20*(1), 90–96. https://doi.org/10.1016/j.jcrc.2004.11.004

Pratt, L. W., Ferlito, A., & Rinaldo, A. (2008). Tracheotomy: Historical review. *The Laryngoscope*, *118*(9), 1597–1606. https://doi.org/10.1097/MLG.0b013e3181783a4c

Rasmussen, L. A., Bell, E., & Racine, E. (2016). A qualitative study of physician perspectives on prognostication in neonatal hypoxic ischemic encephalopathy. *Journal of Child Neurology*, *31*(11), 1312–1319. https://doi.org/10.1177/0883073816656400

Renjilian, C. B., Womer, J. W., Carroll, K. W., Kang, T. I., & Feudtner, C. (2013). Parental explicit heuristics in decision-making for children with life-threatening illnesses. *Pediatrics*, *131*(2), e566–e572. https://doi.org/10.1542/peds.2012-1957

Roscigno, C. I., Savage, T. A., Kavanaugh, K., Moro, T. T., Kilpatrick, S. J., Strassner, H. T., Grobman, W. A., & Kimura, R. E. (2012). Divergent views of hope influencing communications between parents and hospital providers. *Qualitative Health Research*, *22*(9), 1232–1246. https://doi.org/10.1177/1049732312449210

Shaffer, V. A., & Zikmund-Fisher, B. J. (2013). All stories are not alike: A purpose-, content-, and valence-based taxonomy of patient narratives in decision aids. *Medical Decision Making*, *33*(1), 4–13. https://doi.org/10.1177/0272989X12463266

Thyen, U., Kuhlthau, K., & Perrin, J. M. (1999). Employment, child care, and mental health of mothers caring for children assisted by technology. *Pediatrics*, *103*(6), 1235–1242. https://doi.org/10.1542/peds.103.6.1235

Tilden, V. P., Tolle, S. W., Nelson, C. A., & Fields, J. (2001). Family decision-making to withdraw life-sustaining treatments from hospitalized patients. *Nursing Research*, *50*(2), 105–115. https://doi.org/10.1097/00006199-200103000-00006

Van Cleave, A. C., Roosen-Runge, M. U., Miller, A. B., Milner, L. C., Karkazis, K. A., & Magnus, D. C. (2014). Quality of communication in interpreted versus noninterpreted PICU family meetings. *Critical Care Medicine*, *42*(6), 1507–1517. https://doi.org/10.1097/CCM.0000000000000177

Vig, E. K., Starks, H., Taylor, J. S., Hopley, E. K., & Fryer-Edwards, K. (2007). Surviving surrogate decision-making: What helps and hampers the experience of making medical decisions for others. *Journal of General Internal Medicine*, *22*(9), 1274–1279. https://doi.org/10.1007/s11606-007-0252-y

Wilfond, B. S. (2014). Tracheostomies and assisted ventilation in children with profound disabilities: Navigating family and professional values. *Pediatrics*, *133*(Suppl. 1), S44–S49. https://doi.org/10.1542/peds.2013-3608H

Wilson, T. D., & Gilbert, D. T. (2003). Affective forecasting. In M. P. Zanna (Ed.), *Advances in experimental social psychology* (Vol. 35, pp. 345–411). Academic Press. https://doi.org/10.1016/S0065-2601(03)01006-2

Wilson, T. D., & Gilbert, D. T. (2005). Affective forecasting: Knowing what to want. *Current Directions in Psychological Science*, *14*(3), 131–134. https://doi.org/10.1111/j.0963-7214.2005.00355.x

Wise, M., Han, J. Y., Shaw, B., McTavish, F., & Gustafson, D. H. (2008). Effects of using online narrative and didactic information on healthcare participation for breast cancer patients. *Patient Education and Counseling*, *70*(3), 348–356. https://doi.org/10.1016/j.pec.2007.11.009

Yaneza, M. M. C., James, H. L., James, H. P., Davies, P., Harrison, S., McAlorum, L., Clement, W. A., & Kubba, H. (2015). Changing indications for paediatric tracheostomy and the role of a multidisciplinary tracheostomy clinic. *The Journal of Laryngology and Otology*, *129*(9), 882–886. https://doi.org/10.1017/S0022215115001140

Yates, J. F. (2003). *Decision management: How to assure better decisions in your company* (Vol. 29). Jossey-Bass.

Yates, J. F., Veinott, E. S., & Patalano, A. L. (2003). Hard decisions, bad decisions: On decision quality and decision aiding. In S. L. Schneider & J. Shanteau (Eds.), *Emerging perspectives on judgment and decision research* (pp. 13–63). Cambridge University Press. https://doi.org/10.1017/CBO9780511609978.003

Chapter 1 Parent Experiences and Considerations When Facing Tracheostomy Decisions for a Critically Ill Child

Introduction

Tracheotomy has been increasingly performed on critically ill children with conditions that require prolonged mechanical ventilation (Gergin et al., 2016; Lewis et al., 2003; Watters, 2017; Yaneza et al., 2015). Many of the tracheostomy decisions are preference-sensitive, as both pursuing tracheostomy or not would be reasonable options for the patient's condition. Pediatric tracheostomy decisions are often difficult, in part due to limited options at the time of decision making. Tracheostomy is often the only option to optimize chances of long-term survival as compared to alternatives (Nageswaran, Golden, et al., 2018), such as continued intubation, other noninvasive breathing support, and palliative care. Parents have to weigh the benefits and risks of tracheostomy along with their values related to survival and quality of life (Antommaria et al., 2015; Deutsch, 2010), while the diagnoses of underlying conditions and long-term prognosis may be uncertain (Nageswaran, Hurst, et al., 2018; Rasmussen et al., 2016).

For this kind of value-laden decision where both pursuing a tracheostomy placement or not are reasonable choices, shared decision making has been recommended for clinicians and parents to discuss medical information and to consider options that are in the best interest of the child and family (Kon et al., 2016; Politi et al., 2013). However, clinicians and parents may hold different values and considerations when making the decision (Lam et al., 2009; Needle et al., 2012) and clinicians may not be trained to properly communicate the decision and relevant information (Nelson et al., 2006, 2007). As a result, parents may experience undue stress and decisional regret during and after decision making (Anderson et al., 2008; Muscara et al., 2015; October et al., 2020). Therefore, a better understanding of parents' needs and values is important for mutually satisfactory shared decision making.

Although studies have examined parent caregivers' experiences after tracheostomy placement (Flynn et al., 2013; Gong et al., 2019; Westwood et al., 2019), little is known about how parents make these decisions. Therefore, the aim of this study was to characterize parents' decision process when considering tracheostomy for their critically ill children.

Method

We conducted semi-structured interviews of parents regarding their tracheostomy decision processes for their critically ill child. The interviews took place at a large Midwestern children's hospital from April 2018 to August 2019. The University of Michigan Medical School Institutional Review Board (IRBMED) approved the study protocol.

Participants

Parents (biological or legal guardian) who just made a value-laden tracheostomy decision for their critically-ill child during the study data collection period were eligible for participation.

Our study team contacted the intensive care unit medical teams weekly to ask whether there were critically ill children for whom a tracheostomy decision had been discussed with parents and a decision had just been made. A research coordinator in the unit approached the parents and asked for their consent to be contacted by the study team. Potential participants were told that the study team sought to better understand the decision processes of parents of critically ill children considering a tracheostomy placement. Once the parent agreed, the study team contacted the parent to set up a time for a one-hour interview. All parents approached agreed to be contacted by the study team. A total of 17 parents were interviewed.

Data Collection

Clinical psychologists (P.D., S.GB) and research staff (H.Y., R.M.) conducted the semi-structured interviews (median length = 36 min, range 26–69 min) in person (*n* = 12, in the hospital) or via phone (*n* = 5) based on mutual availability by the participants and interviewers. Written informed consent for interviewing, audio recording the interviews, and retrieving relevant information needed for the study (e.g., the child patient's medical record) was obtained from each participant. Participants were asked to provide self-reported demographics and received a $50 gift card as an honorarium for their time and participation. Interviewers used an interview guide that was developed based on the Cardinal Issue Perspective (CIP) of decision making (Yates, 2003). We revised the guide substantially after the first 5 interviews to better capture participants' perceptions of the decision process (Appendix A). To this end, we added questions to elicit parents' emotions during decision making, feelings about having a choice, perceptions of most valued treatments' upsides and downsides, tradeoffs, interpretations of quality of life and child's best interests, and regret. Starting with the 6th participant, the interviewer provided a verbal summary of responses to each participant at the conclusion of the interview, who had the opportunity to correct and refine their responses. We obtained the child's demographic and diagnostic information from their medical records.

Data Analysis

Due to the addition of substantial important new interview questions, we considered the first 5 interviews to be pilot interviews and excluded them from the final analysis. Therefore, the unit of analysis was the 12 interviews conducted after the addition of the revised interview questions. Three undergraduate research assistants and one author (H.Y.) transcribed each audio-recorded interview verbatim and checked each for accuracy and completeness.

We summarized demographic and medical information using descriptive statistics. We analyzed the qualitative data using content analysis (Morse & Field, 1995). Two experienced qualitative researchers (H.Y. and C.AE) independently read all the transcripts multiple times to familiarize themselves with data and proposed initial coding categories and emerging themes. In addition, a third experienced qualitative researcher, who also is a medical clinician (S.K.), read three representative transcripts and identified emerging themes, which agreed with those derived from the two primary coders (H.Y. and C.AE). After the development of a coding scheme, coder H.Y. sorted the data into coding categories. Once all transcripts had been coded, coder C.AE reviewed the data analysis. Then, after review and interactive discussions, the two primary coders refined coding as needed.

Data saturation was reached when redundancy and no additional information emerged. In the end, agreement for theme extraction and coding reached 100% agreement using the Miles and Huberman formula $\frac{Number\ of Agreements}{Total\ Number\ of\ Agreements\ and\ Disagreements}$ (Miles & Huberman, 1994). The identified themes and supporting statements were reviewed for accuracy and completeness to ensure that they were comprehensive.

Results

Table 1.1 provides a description of the characteristics of the 12 parent interviewees and their children included in the analysis.

Table 1.1 Participant Characteristics

Characteristics	Value*
Children whose parents participated in interviews (n = 12)	
Age, median (range)	180 (57–5320) days
Sex, n (%)	
Boys	8 (67)
Girls	4 (33)
Primary diagnostic categories, n (%)	
Genetic conditions	5 (42)
Prematurity/Bronchopulmonary dysplasia	3 (25)
Brain injury/malformation	3 (25)
Heart conditions	1 (8)
Final decision, n (%)	
Tracheostomy	10 (83)
No tracheostomy placed	2 (17)
Parents who participated in interviews (n = 12)	
Age, median (range)	31.5 yrs (19–63 yrs)
Relationship to the child	
Biological mother	11 (92)
Legal guardian	1 (8)
Race, n (%)	
White	9 (75)
Black or African American	3 (25)
Religion, n (%)	
Christian/Catholic/Baptist	9 (75)
None indicated	1 (8)
Rather not say	1 (8)
Missing	1 (8)
Marital status, n (%)	
Married	4 (33)
Unmarried (including other: single, engaged)	8 (67)
Education, n (%)	
Some or no high school	3 (25)
High school	1 (8)
Some college	3 (25)
College graduate	3 (25)
Master's degree or higher	2 (17)
Household income, n (%)	
<$30,000	2 (17)
$30,000-$50,000	1 (8)
$50,000-$90,000	4 (33)
>$90,000	1 (8)
Rather not say	4 (33)

*to date of the interview

Six primary themes emerged from the analysis of the qualitative data, which included revision and refinement of coding. Some codes were refined into additional themes and subthemes. For example, the original category "support from other people/information" was refined into a major theme “seeking support” (with subthemes of “information about tracheostomy and home care” and “emotional support from peer parents”) and a minor theme “other support/information seeking behaviors” (e.g., family and friends as general support, not included in the main findings). The initial theme of “emotional difficulties and worries” was refined to subthemes of “stressful emotional state,” “coping with stress,” “worries about the home care and family’s/caregivers’ quality of life with tracheostomy,” and “worries about child’s well-being with tracheostomy.” After deliberation and review, we ultimately reduced and combined some other themes. The unmet needs for emotional and information support categories were combined into the “seeking support” main theme. Upsides and downsides of tracheostomy were combined into the hopes and worries of tracheostomy categories.

In the following section, the major themes are presented in a similar order to when decision issues appear in any decision process according to the Cardinal Issue Perspective: *Mode* (seeking support), *Investment* (stress), *Options/Tradeoffs* (considerations of options and perceptions of tracheostomy over time), and *Value/Possibilities/Implementation* (quality and length of life, faith and religious beliefs). Additional narrative data are found in Appendix B.

Theme 1: Seeking Support

Information about Tracheostomy and Home Care

All parents reported seeking and desiring various types of information, mainly in response to questions that asked about consultations with other people/materials for decision making and wishes for decision support. For instance, parents reported searching information online, stating “what the tracheotomy surgery would entail, the overall care of it [tracheostomy]” and “different lifestyle changes, like what can they do with the trach what they can’t do with the trach.” Three parents reported searching for “trach babies” videos (e.g., on YouTube) to visualize everyday life. Moreover, peer parents (in-person or online support groups) were identified as important sources of information. Parents asked peer parents questions about “trach care, trach management, emergency,” “what our life would be like,” and “how it was going, how long they were on it [tracheostomy]” and wanting to know “their story and life with it.” Parents reported asking nurses “a lot of questions” and wanting more information from the providers, such as “it would have been nice to have the trach itself to say this is what it looks like,” “trach care done on another child,” and “more paperwork on it [tracheostomy].”

Emotional Support from Peer Parents

Many parents desired emotional support from peer parents who were faced with tracheostomy decisions for their critically ill children. Parents described that support from these parents as “more beneficial” than that offered by clinicians and staff. Parents perceived that peer parents made them “feel not alone” and “a lot more comfortable with the decision,” as they provided “encouragement” and said that “everything [is] gonna [sic] be okay.” However, parents shared that “a network of support, not just call a doctor if you have a question” was needed but was often lacking. They also described wanting “more support from other families that have tracheostomy babies” and felt “there was no one else for me” and “walking around numb for months” because they did not have peer parents to talk to for support.

Theme 2: Stress

Throughout the interview, and when specifically asked about their emotions during decision making, parents described their feelings and ways to cope with stress.

Stressful Emotional State

Six parents reported that the decision process was highly or extremely difficult, while four others reported it as somewhat difficult and two parents stated that it was not difficult at all.

Parents described the process as “a traumatic experience.” It was “emotional, stressed, depressed” and “overwhelming” and put “a lot of strain on our family.” Some parents described “going through depression” and having “a lot of psychiatric illnesses.”

Coping with Stress

Parents had various ways of managing stress. For example, some indicated that they coped with stress by “learning,” “trying to stay busy” and “stay[ing] in today.” Some talked to families and friends. Others saw “a therapist” and took “antidepressant” medications.

Theme 3: Considerations of Options

Perception of Choice

Parents described being presented with alternatives to tracheostomy, such as “comfort care” ($n = 6$), waiting and keeping intubation ($n = 6$), and other surgeries ($n = 5$). However, four parents perceived that there were ‘no real’ choices—one parent thought “that [tracheostomy] was what she was supposed to do” and one parent indicated that “[tracheostomy] was basically her only option at survival.”

Tradeoffs

Primarily in response to questions eliciting parents’ perceptions and resolutions of tradeoffs, the participants reported tradeoffs among tracheostomy and its alternatives. One major tradeoff parents considered was the benefits of tracheostomy (e.g., “a stable airway”) in exchange for normalcy of both the child’s and family’s life. For instance, one parent stated that “a more normal life…and less scary life, especially before this was, we started this process, was the tradeoff for her being able to breathe and live.” Some other parents also saw the core tradeoff as shorter life without this invasive procedure or prolongation of life with it, but “let her pass” was not an option.

Theme 4: Perceptions of Tracheostomy Over Time

Throughout the interview, parents talked about their attitudes towards tracheostomy. Most parents had immediate resistance to tracheostomy when doctors brought it up initially, as they indicated that “I just dismissed it instantly” and it was “almost like a denial.” One parent reported “no hesitation” because “survival” was so important and the child “was capable of” going through tracheostomy. The reasons of resistance varied. One parent reported being “scared” of “cut[ting] my baby’s throat.” Some parents had the hope that they could “avoid a trach” and the condition would “fix itself.” One parent who was very religious said that she did not “believe that’s [tracheostomy] part of God’s plan for anybody.” Several parents were overwhelmed by “the unknown” of future life and “lack of knowledge.” One parent said she did not see “proof” that her child needed a tracheostomy.

Nevertheless, many parents came to accept tracheostomy in the end, although in the meantime they still held the hope that the child would not “need this [tracheostomy] forever.” Parents “took some time to think it [tracheostomy] through” and “got used to it [tracheostomy].” “Talking to doctors and getting research” helped “make the decision.” Talking to their partner also helped decision making. The most salient reason parents reported was that they later came to the conclusion that their child “need[ed]” a tracheostomy, which would “help [the child] out a lot.”

Theme 5: Quality and Length of Life

Throughout the interview and when asked about upsides of tracheostomy and their considerations of their child’s quality of life and length of life, parents reported their values and hopes.

Hopes/Goals/Values

Parents understood of the benefits of tracheostomy, such as providing "a secured airway," enabling the child to "be more comfortable," to "develop," and to "move forward," and raising the possibility of "coming home and having our family together."

Perceptions and Considerations of Best Quality of Life

All parents discussed quality of life for their children. In general, they described valuing "moving forward," "having a chance [for their child] to grow and develop," and "going home," and "comfort." Nonetheless, parents described different expectations. For example, one parent viewed "breathing" as "ultimately so important," while another parent described valuing "talking, walking, expressing his self." Others described thinking about the opportunity to "experience things like a normal baby" and "grow up and be a normal kid."

Perceptions and Considerations of Survival and Length of Life

Five parents also considered length of life very important and described "terminating life once it's here" as unacceptable. They described that "it was either life or no life" and that they wanted their children to live "as long as possible." A few parents mentioned that they would not choose tracheostomy if their children would not make improvement and were suffering, e.g., "it would be different if he was in pain or suffering or something like that or you know if he was gonna [sic] be a vegetable."

Throughout the interview and when asked about their perceptions of downsides of tracheostomy, parents described their worries about the child's and their own quality of life.

Worries about Child's Well-Being with Tracheostomy

Parents expressed concern about the uncertainty of "the need for a ventilator" as that could be "lifelong." Parents also described trying to judge "how long it would be" and whether it "can it be reversed." Parents thought that with a tracheostomy, their child "wouldn't be able to be a normal baby." They were also worried about "pain," "wound break/scar," and "infection." Parents were afraid that if "it would get plugged…he wouldn't be able to breathe." One important life-changing downside of tracheostomy that parents described for their children was "not being able to talk."

Worries about Home Care and Family's/Caregivers' Quality of Life with Tracheostomy

Parents described that it seemed "nerve-wracking" to deal with tracheostomy at home alone, especially the "airway emergency" because of not knowing "how it [tracheostomy] worked." Moreover, the long-term care put "financial strain" and made caregivers "homebound." For instance, parents worried about "fair(ness) to [my] other kids" or "resentment in [my] kids" and going on "parades and Christmas tree lightings" or "vacation" with a child on tracheostomy and ventilator. One parent explicitly mentioned that home nursing made her "nervous" and she thought "I'm not gonna [sic] like the first couple of nurses." Parents also mentioned unwanted sympathy and rude comments from strangers that "people just look at you."

Theme 6: Faith and Religious Beliefs

Faith and religious beliefs were important in decision making. Seven parents explicitly described that they were praying for their child. They "trusted Him" and believed that "God is in control." Parents had faith in "miracles" and hoped that "even though she has that [tracheostomy] she's not going to have it forever." One parent who stated not being very religious, still sought God for strength: "I'm not even very Christian…but I, I needed something. So I did I just gave everything to God and I just prayed."

Discussion

This study is among the first to investigate how parents considered and made tracheostomy decisions for their critically ill children shortly after the decisions had been made. Parents described desiring lots of information for decision making—not only about tracheostomy, but also about daily routine changes and quality of life for their child and their family. Parents viewed peer parents who had similar experiences helpful in terms of providing relevant outpatient information and emotional comfort. Parents described the decision process as stressful and that they had to find ways to cope with the stress. Parents faced alternatives and tradeoffs and many parents described being initially opposed to tracheostomy due to worries, uncertainty, and unfamiliarity with tracheostomy, but after careful considerations of the child's needs, many eventually agreed. Parents' expectations of quality of life were diverse, but nearly all indicated that they believed tracheostomy would give their children a better chance and outlook at life, although they worried about their abilities to handle home care and any negative impact on their child. Religious beliefs also played an important role in decision making.

Narrative data from parents indicated that when making the decisions, they had to learn a lot about the child's condition and tracheostomy and that they had many questions about future life with a tracheostomy. However, uncertainty and a lack of support made the decision process difficult. Therefore, giving parents time and information may help them deliberate tracheostomy and other options. This is consistent with findings from October et al. (2014) who reported that parents most frequently mentioned "keeping us informed" as the key to help decision making.

Our study revealed two main types of information parents sought to make informed decisions: the influences of tracheostomy on the child and family. One type of needed information was the impact of the tracheostomy on their child, including a visual demonstration of the tracheotomy procedure, an explanation of the prognosis (how long will a tracheostomy be needed, will a ventilator be needed,) and exploration of their child’s physical and emotional well-being. This finding is consistent with previous literature that reported parents considered openly discussing and understanding illness (concept, severity, end results, uncertainty) and treatments as important for decision making (Allen, 2014; Xafis et al., 2015). The second type of needed information was the home care of a child with tracheostomy. Parents would need this information to accurately assess whether or not they would be capable of providing the care and to assess the resources they would need in order to adequately prepare and care for their child at home. However, hospital-based physicians may not be the best source for communicating long-term outcomes related to managing everyday life for a child with a tracheostomy living at home because of limited outpatient experiences. This echoes findings from previous studies about information needs regarding long-term care and emotional experiences (Edwards et al., 2019), especially from caregivers with similar experiences (Carnevale et al., 2006; McCormick et al., 2015), to help prepare parents considering tracheostomy better understand diverse outcomes and choices (Janvier et al., 2012; Montagnino & Mauricio, 2004).

It is also interesting to note that parents considered their children’s needs and best interests, which drove their ultimate acceptance of tracheostomy, even though they had varied beliefs about acceptable quality of life. While most parents in our study adjusted their expectations and focused more on survival, comfort in breathing, and a chance to go home and develop, only a few expressed hopes for functional independence or a normal life for their child. This finding is similar to findings in the literature that parents value providing every opportunity within reason to improve their children’s capabilities (Janvier et al., 2016; Kirschbaum, 1996), while physicians tend to value cognitive functioning and independent living (Lam et al., 2009;

Wilfond, 2014). On the other hand, these considerations focused more on short-term outcomes rather than long-term outcomes as the child grows much older. One reason could be that physicians tend to communicate medical information, in particular focusing on discussing benefits rather than risks of tracheostomy (Hebert et al., 2017), but not implications of the decision in the long term (Boss et al., 2017; Lemmon et al., 2019). Therefore, it is important for physicians to communicate balanced, big-picture information and respect different values in decision making (Daboval et al., 2016; Wilfond, 2014).

This study has several limitations. First, there was no opportunity to present study results to the participants to obtain feedback and confirm the final derived themes, although the interviewers asked the participants to confirm a summary of their responses at the end of the interview. Second, there may be a selection bias among parents who chose to participate, in particular in that most participants chose tracheostomy. Third, the sample size was small. Nonetheless, our participants provided rich narrative data that described a variety of experiences and data saturation was reached.

Despite the limitations, the study has implications for patient-centered practice and future research. These comprehensive qualitative data provide clinicians with parents' perspectives. By learning these experiences, clinicians may become more mindful about and responsive to parents' preferences, needs, and values when discussing these decisions. In addition, as parents found the decision process stressful and desired more information, providers need to improve patient education and communication to facilitate decision making. In particular, it is important to help parents understand both short-term and long-term impact of a tracheostomy placement on the child and the family. As the lack of information and preparation is a major contributor to parental decisional conflict, decisional regret, and impairment of quality of life (October et al., 2020), providing above-mentioned support may improve parents' decision process and outcomes. Future research can investigate how to communicate such information with parents to reduce their stress and improve satisfaction with their decision-making experience.

Conclusion

Our qualitative analysis of parents' tracheostomy decision making highlights their need for information and diverse views of quality of life when making emotionally-charged decisions. This suggests opportunities to improve shared decision making between physicians and parents by providing parents with needed information about outpatient experiences and respecting each family's own values. Future research is warranted to examine whether improvements in practice lead to increased parental satisfaction regarding the decision process and its outcomes.

References

Allen , K. A. (2014). Parental decision-making for medically complex infants and children: An integrated literature review. *International Journal of Nursing Studies*, *51*(9), 1289–1304. https://doi.org/10.1016/j.ijnurstu.2014.02.003

Anderson, W. G., Arnold, R. M., Angus, D. C., & Bryce, C. L. (2008). Posttraumatic stress and complicated grief in family members of patients in the intensive care unit. *Journal of General Internal Medicine*, *23*(11), 1871–1876. https://doi.org/10.1007/s11606-008-0770-2

Antommaria, A. H. M., Collura, C. A., Antiel, R. M., & Lantos, J. D. (2015). Two infants, same prognosis, different parental preferences. *Pediatrics*, *135*(5), 918–923. https://doi.org/10.1542/peds.2013-4044

Boss, R. D., Lemmon, M. E., Arnold, R. M., & Donohue, P. K. (2017). Communicating prognosis with parents of critically ill infants: Direct observation of clinician behaviors. *Journal of Perinatology*, *37*(11), 1224–1229. https://doi.org/10.1038/jp.2017.118

Carnevale, F. A., Alexander, E., Davis, M., Rennick, J., & Troini, R. (2006). Daily living with distress and enrichment: The moral experience of families with ventilator-assisted children at home. *Pediatrics*, *117*(1), e48–e60. https://doi.org/10.1542/peds.2005-0789

Daboval, T., Shidler, S., & Thomas, D. (2016). Shared decision making at the limit of viability: A blueprint for physician action. *PloS One*, *11*(11), Article e0166151. https://doi.org/10.1371/journal.pone.0166151

Deutsch, E. S. (2010). Tracheostomy: Pediatric considerations. *Respiratory Care*, *55*(8), 1082–1090.

Edwards, J. D., Panitch, H. B., Nelson, J. E., Miller, R. L., & Morris, M. C. (2019). Decisions for long-term ventilation for children: Perspectives of family members. *Annals of the American Thoracic Society*, *17*(1), 72–80. https://doi.org/10.1513/AnnalsATS.201903-271OC

Flynn, A. P., Carter, B., Bray, L., & Donne, A. J. (2013). Parents' experiences and views of caring for a child with a tracheostomy: A literature review. *International Journal of Pediatric Otorhinolaryngology*, *77*(10), 1630–1634. https://doi.org/10.1016/j.ijporl.2013.07.020

Gergin, O., Adil, E. A., Kawai, K., Watters, K., Moritz, E., & Rahbar, R. (2016). Indications of pediatric tracheostomy over the last 30 years: Has anything changed? *International Journal of Pediatric Otorhinolaryngology*, *87*, 144–147. https://doi.org/10.1016/j.ijporl.2016.06.018

Gong, S., Wang, X., Wang, Y., Qu, Y., Tang, C., Yu, Q., & Jiang, L. (2019). A descriptive qualitative study of home care experiences in parents of children with tracheostomies. *Journal of Pediatric Nursing*, *45*, 7–12. https://doi.org/10.1016/j.pedn.2018.12.005

Hebert, L. M., Watson, A. C., Madrigal, V., & October, T. W. (2017). Discussing benefits and risks of tracheostomy: What physicians actually say. *Pediatric Critical Care Medicine*, *18*(12), e592–e597. https://doi.org/10.1097/PCC.0000000000001341

Janvier, A., Farlow, B., & Barrington, K. J. (2016). Parental hopes, interventions, and survival of neonates with trisomy 13 and trisomy 18. *American Journal of Medical Genetics Part C: Seminars in Medical Genetics*, *172*(3), 279–287. https://doi.org/10.1002/ajmg.c.31526

Janvier, A., Farlow, B., & Wilfond, B. S. (2012). The experience of families with children with trisomy 13 and 18 in social networks. *Pediatrics*, *130*(2), 293–298. https://doi.org/10.1542/peds.2012-0151

Kirschbaum, M. S. (1996). Life support decisions for children: What do parents value? *Advances in Nursing Science*, *19*(1), 51–71. https://doi.org/10.1097/00012272-199609000-00007

Kon, A. A., Davidson, J. E., Morrison, W., Danis, M., & White, D. B. (2016). Shared decision making in ICUs: An American College of Critical Care Medicine and American Thoracic Society policy statement. *Critical Care Medicine*, *44*(1), 188–201. https://doi.org/10.1097/CCM.0000000000001396

Lam, H. S., Wong, S. P. S., Liu, F. Y. B., Wong, H. L., Fok, T. F., & Ng, P. C. (2009). Attitudes toward neonatal intensive care treatment of preterm infants with a high risk of developing long-term disabilities. *Pediatrics*, *123*(6), 1501–1508. https://doi.org/10.1542/peds.2008-2061

Lemmon, M. E., Huffstetler, H., Barks, M. C., Kirby, C., Katz, M., Ubel, P. A., Docherty, S. L., & Brandon, D. (2019). Neurologic outcome after prematurity: Perspectives of parents and clinicians. *Pediatrics*, *144*(1), Article e20183819. https://doi.org/10.1542/peds.2018-3819

Lewis, C. W., Carron, J. D., Perkins, J. A., Sie, K. C. Y., & Feudtner, C. (2003). Tracheotomy in pediatric patients: A national perspective. *Archives of Otolaryngology–Head & Neck Surgery*, *129*(5), 523–529. https://doi.org/10.1001/archotol.129.5.523

McCormick, M. E., Ward, E., Roberson, D. W., Shah, R. K., Stachler, R. J., & Brenner, M. J. (2015). Life after tracheostomy: Patient and family perspectives on teaching, transitions, and multidisciplinary teams. *Otolaryngology–Head and Neck Surgery*, *153*(6), 914–920. https://doi.org/10.1177/0194599815599525

Miles, M. B., & Huberman, A. M. (1994). *Qualitative data analysis: An expanded sourcebook*. SAGE Publications.

Montagnino, B. A., & Mauricio, R. V. (2004). The child with a tracheostomy and gastrostomy: Parental stress and coping in the home–a pilot study. *Pediatric Nursing*, *30*(5), 373–380, 401.

Morse, J. M., & Field, P. A. (1995). *Qualitative research methods for health professionals* (2nd ed.). SAGE publications.

Muscara, F., Burke, K., McCarthy, M. C., Anderson, V. A., Hearps, S. J., Hearps, S. J., Dimovski, A., & Nicholson, J. M. (2015). Parent distress reactions following a serious illness or injury in their child: A protocol paper for the take a breath cohort study. *BMC Psychiatry*, *15*, Article 153. https://doi.org/10.1186/s12888-015-0519-5

Nageswaran, S., Golden, S. L., Gower, W. A., & King, N. M. P. (2018). Caregiver perceptions about their decision to pursue tracheostomy for children with medical complexity. *The Journal of Pediatrics*, *203*, 354–360.e1. https://doi.org/10.1016/j.jpeds.2018.07.045

Nageswaran, S., Hurst, A., & Radulovic, A. (2018). Unexpected survivors: Children with life-limiting conditions of uncertain prognosis. *American Journal of Hospice and Palliative Medicine*, *35*(4), 690–696. https://doi.org/10.1177/1049909117739852

Needle, J. S., Mularski, R. A., Nguyen, T., & Fromme, E. K. (2012). Influence of personal preferences for life-sustaining treatment on medical decision making among pediatric intensivists. *Critical Care Medicine*, *40*(8), 2464–2469. https://doi.org/10.1097/CCM.0b013e318255d85b

Nelson, J. E., Angus, D. C., Weissfeld, L. A., Puntillo, K. A., Danis, M., Deal, D., Levy, M. M., Cook, D. J., & Critical Care Peer Workgroup of the Promoting Excellence in End-of-Life

Care Project. (2006). End-of-life care for the critically ill: A national intensive care unit survey. *Critical Care Medicine*, *34*(10), 2547–2553. https://doi.org/10.1097/01.CCM.0000239233.63425.1D

Nelson, J. E., Mercado, A. F., Camhi, S. L., Tandon, N., Wallenstein, S., August, G. I., & Morrison, R. S. (2007). Communication about chronic critical illness. *Archives of Internal Medicine*, *167*(22), 2509–2515. https://doi.org/10.1001/archinte.167.22.2509

October, T. W., Fisher, K. R., Feudtner, C., & Hinds, P. S. (2014). The parent perspective: "Being a good parent" when making critical decisions in the PICU. *Pediatric Critical Care Medicine*, *15*(4), 291–298. https://doi.org/10.1097/PCC.0000000000000076

October, T. W., Jones, A. H., Greenlick Michals, H., Hebert, L. M., Jiang, J., & Wang, J. (2020). Parental conflict, regret, and short-term impact on quality of life in tracheostomy decision-making. *Pediatric Critical Care Medicine*, *21*(2), 136–142. https://doi.org/10.1097/PCC.0000000000002109

Politi, M. C., Lewis, C. L., & Frosch, D. L. (2013). Supporting shared decisions when clinical evidence is low. *Medical Care Research and Review*, *70*(Suppl. 1), 113S–128S. https://doi.org/10.1177/1077558712458456

Rasmussen, L. A., Bell, E., & Racine, E. (2016). A qualitative study of physician perspectives on prognostication in neonatal hypoxic ischemic encephalopathy. *Journal of Child Neurology*, *31*(11), 1312–1319. https://doi.org/10.1177/0883073816656400

Watters, K. F. (2017). Tracheostomy in infants and children. *Respiratory Care*, *62*(6), 799–825. https://doi.org/10.4187/respcare.05366

Westwood, E. L., Hutchins, J. V., & Thevasagayam, R. (2019). Quality of life in paediatric tracheostomy patients and their caregivers – a cross-sectional study. *International*

Journal of Pediatric Otorhinolaryngology, *127*, Article 109606. https://doi.org/10.1016/j.ijporl.2019.109606

Wilfond, B. S. (2014). Tracheostomies and assisted ventilation in children with profound disabilities: Navigating family and professional values. *Pediatrics*, *133*(Suppl. 1), S44–S49. https://doi.org/10.1542/peds.2013-3608H

Xafis, V., Wilkinson, D., & Sullivan, J. (2015). What information do parents need when facing end-of-life decisions for their child? A meta-synthesis of parental feedback. *BMC Palliative Care*, *14*(1), Article 19. https://doi.org/10.1186/s12904-015-0024-0

Yaneza, M. M. C., James, H. L., James, H. P., Davies, P., Harrison, S., McAlorum, L., Clement, W. A., & Kubba, H. (2015). Changing indications for paediatric tracheostomy and the role of a multidisciplinary tracheostomy clinic. *The Journal of Laryngology and Otology*, *129*(9), 882–886. https://doi.org/10.1017/S0022215115001140

Yates, J. F. (2003). *Decision management: How to assure better decisions in your company* (Vol. 29). Jossey-Bass.

Chapter 2 Using Narratives to Correct Forecasting Errors in Pediatric Tracheostomy Decision Making

Introduction

Parents of critically ill children who have long-term breathing problems are often asked to consider whether to have their child receive a tracheostomy, which provides a stable airway for patients who need prolonged breathing support (Nelson & Mahant, 2014; Watters, 2017; Wilfond, 2014). Tracheostomy decisions are high-stakes and difficult because they are often a choice between long-term survival and death. In addition, pursuing a tracheostomy placement has long-term implications for the quality of life of the child and caregivers. For instance, the child may lead a limited life and need substantial support from the community (e.g., school) to accomplish activities. Moreover, 24/7 home care of the child by skilled healthcare providers and caregivers impacts the quality of home and social life for the caregivers (Carnevale et al., 2006; Flynn et al., 2013; Garrubba et al., 2009; Hopkins et al., 2009; Janvier et al., 2012; McCormick et al., 2015; Thyen et al., 1999).

The tracheostomy decision is a situation in which forecasting errors—inaccurate forecasting of the future (e,g., Gilovich et al., 2002; Wilson & Gilbert, 2003)—are both common and likely consequential. Parents are unlikely to have experience in making these decisions or caring for a child with tracheostomy. As a result, it may be challenging for them to envision and accurately evaluate possible decision outcomes. Consequently, parents may feel distressed about decision making and consequences of the decision such as challenges of finding satisfactory home care, impact on family relationships (Carnevale et al., 2006; McCormick et al., 2015), particularly if they felt that in retrospect that they had not been well informed by clinicians about the decision (Allen, 2014; McCormick et al., 2015; October et al., 2020). Our research identified different types of possible forecasting errors and oversight that parents are likely to make during these difficult decisions.

In this study, we explored the possibility of correcting forecasting errors related to tracheostomy decision making through the use of targeted narratives. Specifically, we created a scenario in which parents were asked to make a tracheostomy decision for their hypothetical neurologically-impaired child. We then constructed narratives describing other parents' experiences of their child's and their family's long-term quality of life after tracheostomy placement. We primarily examined whether and how these narratives influenced parental tracheostomy decisions and forecasting.

Forecasting Errors

Structurally, tracheostomy placement decisions may be prone to the following biases, some of which are associated with affective forecasting errors—misprediction of the valence, specificity, intensity, or durability of future feelings (Wilson & Gilbert, 2003, 2005). There are also other forecasting errors in situations where patients and family caregivers have to envision their future emotional and physical lives. For instance, patients and caregivers may underestimate their ability to cope with and adapt to worsened health conditions (Halpern & Arnold, 2008).

Focusing Illusion

The focusing illusion, or focalism, is the tendency to put much weight on one set of considerations and, thus, ignore other important considerations when making judgments and decisions (Schkade & Kahneman, 1998). Parents fall prey to focalism at different levels. To begin with, parents tend to focus on survival rather than other potential outcomes. For critically ill children with long-term breathing issues, a tracheostomy placement is often presented as the only option to guarantee long-term survival (Nageswaran et al., 2018). Parents must then face a life-or-death decision for their child. Not choosing to pursue tracheostomy means losing the child, which is seen as unimaginable (Carnevale et al., 2006). Some parents want to try every possible life-sustaining treatment for their child (Carnevale et al., 2011; Michelson et al., 2009).

In addition to focusing on survival, parents and clinicians may focus on immediate outcomes and short-term quality of life. Physicians often limit discussions of tracheostomy decision to the benefits and risks of the procedure as required to obtain informed consent (Nelson et al., 2005), rather than explaining short- or long-term consequences or considerations (Nelson et al., 2007). Physicians are also more likely to discuss benefits (possibility of decannulation and going home, health benefits) than risks (big commitment including long-term tracheostomy home care, ventilator dependence, complications) of tracheostomy, without being aware of doing so (Hebert et al., 2017). As a result of these biases, caregivers of children with tracheostomy may not be fully prepared for possible negative effects on their child, such as loss of voice and limited ability to eat by mouth (Nageswaran et al., 2018). In summary, at the time of decision making, parents' deliberation of tracheostomy may not include a full consideration of the long-term economic, social, and emotional implications of a tracheostomy placement. Therefore, they may make a decision that does not well align with their values, contributing to decisional regret and emotional distress.

Misconstrual

Individuals' construal of the future can sometimes be far different from what will actually happen (as discussed in Gilbert et al., 1998). In the tracheostomy context, parents may misinterpret a placement of tracheostomy as a step towards recovery (Nelson et al., 2005) and predict an optimistic future (Demke et al., 2008) even when clinicians express uncertainty or pessimistic prognosis due to motivated reasoning (Kruger & Burrus, 2004; Kunda, 1990). What is more, people can be over-simplistic when they construe what a distant future event may entail, compared to a near event (Liberman et al., 2002). In this decision, parents may lack the experience and ability to accurately assess many important matters, such as home care challenges, negative impact on family life, and the impact of the child's lagging physical and cognitive development. Studies have found that tracheostomy caregivers encountered logistic difficulties and disruption to family life and received insufficient support for dealing with these challenges (Carnevale et al., 2006; Nageswaran et al., 2018).

Action Bias

The action bias states people's tendency to do something over doing nothing. The tendency to act is prevailing when people are expected to act (Ritov & Baron, 1994). Parents hold good-parent beliefs that they should make every effort to advocate for their child (Feudtner et al., 2015) and choosing not to pursue tracheostomy could therefore be framed as a sign of "giving up." Furthermore, when people anticipate regret resulting from inaction, they are more likely to act (Zeelenberg et al., 2002). People tend to regret more when they behave against the norm for action and receive negative outcomes (Feldman & Albarracín, 2017) and they experience more regret over inaction than action (Gilovich & Medvec, 1994). As such, parents may anticipate substantial regret for not trying everything and thus choose to pursue tracheostomy. However, conforming to norms and avoiding regret may serve the parents' interests rather than the child's well-being.

In summary, these forecasting errors suggest a systematic bias in tracheostomy decision making that may lead some parents to choose tracheostomy even though they would make a different choice if they were better informed. Parents may benefit from information that can help them to understand long-term outcomes of tracheostomy and improve forecasting in the decision making process.

Narratives as Intervention

To help parents understand some long-term consequences of tracheostomy, we chose narratives—“illustrative examples of others’ experiences relevant to the decision” (Bekker et al., 2013, p.2)—as a form to provide relevant information. Studies have demonstrated the effects of narratives on beliefs. For instance, targeted narratives—“narratives that target the direction of a known affective forecasting error” (Shaffer et al., 2016, p.1613), but not narratives that include typical possible experiences, improved accuracy of prediction of discomfort (Shaffer et al., 2016). Narratives reduced perceived barriers to colorectal cancer screening and increased perception of cancer risk (Dillard et al., 2010). “Personal experiences” information help individuals understand the decision and options, evaluate their reasoning, envision potential outcomes of various decisions, and feel supported, depending on personal relevance and narratives’ motives and content (Entwistle et al., 2011). Furthermore, many studies have demonstrated narratives’ effect on behavioral intention, e.g., colorectal cancer screening (Dillard et al., 2010), vaccination (Betsch et al., 2011; De Wit et al., 2008), and exercise intention (Falzon et al., 2015), and healthcare decisions and behaviors, e.g., dialysis and heart disease treatment choice (Ubel et al., 2001; Winterbottom et al., 2012) and skin cancer prevention (Lemal & Van den Bulck, 2010).

Although many studies demonstrate the effectiveness of narratives, review articles present mixed evidence that narratives influence people's beliefs, intention, and behavior in health (Bekker et al., 2013; De Graaf et al., 2016; Winterbottom et al., 2008). To understand this heterogeneity in outcomes, we should first note that all narratives are not identical—they have different content messages, intended purposes, and emotional tones, and therefore varied effects. According to Shaffer and Zikmund-Fisher (2013), there are three types of narratives in terms of information provided: 1) *outcome narratives* (physical or psychological outcomes of a decision); 2) *process narratives* (cognitive process of how a medical decision was made); 3) *experience narratives* (experiences with a treatment or disease). The narratives can also use positive or negative emotional tone. Specifically, *outcome narratives* primarily change the attitudes, intentions, and behaviors of people (e.g., Fagerlin et al., 2005; Shaffer, Scherer, et al., 2018; Ubel et al., 2001). *Process narratives* help people understand important considerations in decision making and increase information searching (Shaffer et al., 2013; Shaffer, Focella, et al., 2018). *Experience narratives*, especially negative stories, are powerful at helping people understand relevant experiences and reduce affective forecasting errors (Angott et al., 2013; Shaffer et al., 2013, 2016; Volandes et. al., 2009, 2010). Therefore, it is the last type of narratives that we used to address forecasting errors in pediatric tracheostomy decision making.

Bearing different types of narratives in mind, the Narrative Immersion Model (Shaffer, Focella, et al., 2018) has identified factors leading to decision makers' engagement with narratives as predictive of the effectiveness of narratives in different situations. The model depicts a continuum of the target audience's engagement—from interest, involvement, to immersion (See Figure 2.1 within the pediatric tracheostomy decision context). It is critical that the target audience process narratives in depth, for instance, immersing oneself in the narratives rather than merely reading and understanding the content. To increase the effectiveness of a narrative, a narrative must appear to be real, credible, and appealing to attract the target audience and the content must allow them to engage in perspective taking and to process the information from the narrative's perspective.

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Figure 2.1 Target Audience's Engagement in the Narratives

Adapted from Figure 1 in "On the Usefulness of Narratives: An Interdisciplinary Review and Theoretical Model," by V. A. Shaffer, E. S. Focella, A. Hathaway, L. D. Scherer, & B. J. Zikmund-Fisher, 2018, *Annals of Behavioral Medicine, 52*(5), p.436 (https://doi.org/10.1093/abm/kax008). Copyright 2018 by Society of Behavioral Medicine.

One advantage of narratives as an intervention strategy is that they have the potential to be acceptable and feasible in clinical practice. Curated narratives that present accurate, decision-relevant information should both align with patients' or parents' desires for information and provide a counterweight to other, less accurate information sources. Furthermore, compared to statistics or technical information, narratives do not require as much cognitive capacity, especially for parents who have lower levels of numeracy and health literacy (e.g., Wise et al., 2008).

Current Study

In an effort to reduce focalism, misconstrual, and action bias, we designed two sets of targeted narratives, drawing parents' attention to decision-making considerations other than survival and possible long-term (mainly negative) outcomes of a tracheostomy placement. One set included two first-person narratives that focused on the child's quality of life (labeled as Baby QOL). Themes included poor long-term outcomes, regret of a decision that led the child to suffer, and the importance of considering long-term quality of life. The other set entailed two first-person narratives that focused on family's quality of life (Family QOL). In this set, themes included the practical difficulty of home care and the negative impact of the tracheostomy decision on family life.

We sought to design narratives that would increase the likelihood of immersing the target audience to achieve our aim to correct forecasting errors. Our narratives mainly included parent stories about what the experience would be like (*experience narrative*) with only limited information about the outcomes and process. This kind of narratives should attract the attention of the target audience (i.e., parents who face similar tracheostomy decisions), because many parents express the desire to learn from other families about what the experience is like and seek information on the internet or from other families (e.g., McCormick et al., 2015). Experience-focused narratives also emphasize changing audiences' information states without necessarily biasing their decisions (Shaffer & Zikmund-Fisher, 2013). To ensure realism, we developed the narratives based on personal experiences of both parents (assessed in prior qualitative research) and clinicians familiar with this type of decision. Moreover, because both the protagonist in the narratives and the target audience are parents, in-group membership should increase the likelihood of perspective taking (Kaufman & Libby, 2012).

Our primary purpose was to determine whether narratives of long-term implications of tracheostomy influence parental decisions—whether or not to pursue tracheostomy for their critically ill child. We hypothesized that parents who had the chance to learn about other parents' perspectives of life with a child with a tracheostomy and receiving mechanical ventilation would be less likely to choose tracheostomy than those who did not get that information (**Hypothesis 1**). We also hypothesized that these narratives would change parents' forecasting about the situation, i.e., increase concern for long-term baby's and/or family's quality of life (**Hypothesis 2**) and that forecasting would correlate with decisions (**Hypothesis 3**). Moreover, we aimed to demonstrate that the effects of narratives on decisions would still be present even after controlling for demographics, beliefs and values, and individual differences (**Hypothesis 4**). Lastly, we explored whether narratives would influence parents' conflict about their decisions, although we did not have a specific hypothesis regarding the direction of influence (**Hypothesis 5**). Specifically, on the one hand, input from other parents would help parents feel more informed, supported, and confident, leading to less decisional conflict. On the other hand, it is possible that this information may contradict their personal beliefs and thus induce more decisional conflict in the short term.

Method

Participants

United States adult Amazon Mechanical Turk (MTurk) participants ($N_{\text{HIT}} > 1000$, approval rate > 98%) were recruited using CloudResearch (formerly TurkPrime, Litman et al., 2017), if they met one of the following criteria: 1) the current age of his or her youngest living child (biological or adoptive) was less than 6 years old; 2) he or she was planning a pregnancy (either first time or another time) with spouse within the next 5 years. We set these criteria to recruit participants who would be likely to have a mindset of rearing a young child because the study required participants to imagine that they had a critically ill baby. The study offered $3 incentive upon completion.

Procedure

The Health Sciences and Behavioral Sciences Institutional Review Board (IRB-HSBS) at the University of Michigan determined that this study was exempt from ongoing review. We administered the study via Qualtrics (Qualtrics, Provo, UT) from February 22nd to March 22nd, 2019. Interested participants first read a consent letter and those who agreed to participate proceeded to screening question(s) to determine eligibility. Eligible participants read a vignette that asked them to imagine participating in a physician-parent meeting about placing a tracheostomy for their hypothetical newborn baby, who was unable to breathe without support due to brain injury. They then answered three questions about the vignette. To ensure that participants fully understood the context for later questions, only those who answered all questions correctly were able to proceed.

Remaining participants were randomly assigned to one of the four conditions that varied in terms of number and type of parent narratives provided: 1) Baby QOL: two parents' narratives of their child's long-term quality of life; 2) Family QOL: two narratives of family's long-term quality of life; 3) Baby QOL + Family QOL: all four narratives; 4) Control: no narratives. Participants who were assigned to one of the experimental conditions read the narratives and answered a reading comprehension question following each narrative. Only those who answered all comprehension questions correctly were able to proceed. Participants assigned to the control condition simply clicked on an arrow to proceed. After reading these materials, participants decided whether to place a tracheostomy for the child and answered eight forecasting questions

(Forecasting Measure) about their judgments and beliefs about the decision and hypothetical child. Participants also completed the Decisional Conflict Scale (DCS; O'Connor, 1995) regarding their decision. Moreover, participants reported their social norm beliefs and values (Social Norm Beliefs and Values Measures) and completed individual differences scales. Participants also provided demographics information (e.g., age, gender, race, education, and income) along with experience with similar decisions (e.g., whether they are a healthcare professional who has experience or expertise in life support decisions, and whether they were involved in life support decision making for a family).

Materials

Vignette

The vignette (Appendix C) depicted a tracheostomy decision for a neurologically-impaired baby. We designed the vignette such that it presented the scenes in a temporal order. The scenes included delivery of the baby, identification of medical issues of the baby, the physician's explanation of the need for a tracheostomy decision, presentation of two options (tracheostomy and no tracheostomy) with descriptions of benefits and risks, and a summary of the decision to be made. The vignette was specifically designed to illustrate decision making between tracheostomy and no tracheostomy (comfort care) when the prognosis was very poor (i.e., the patient had little chance of neurologic recovery and eventual independence), and therefore no tracheostomy (comfort care) was a very reasonable option. Physicians experienced in pediatric tracheostomy decision making reviewed and approved the clinical aspect of the vignette.

Narratives

We developed two sets of narratives (Appendix C) detailing other parents' reflections of the child's and family's quality of life after a tracheostomy placement. Guided by the Narrative Immersion Model (Shaffer, Focella, et al., 2018), we used a systematic procedure to increase the likelihood that the narratives represented realistic experiences of parents who have made the decision and appeal to parents facing the same kind of decision. Although the narratives were fictional, as long as they were accurate and accepted by the audience, they should produce equivalent effects as real stories (Braddock & Dillard, 2016). First, we concluded that other parents' perspectives of lived experience with a child on tracheostomy would have the potential to help understand long-term implications of tracheostomy (e.g., McCormick et al., 2015). Second, we generated an extensive list of specific decision making pitfalls that parents could encounter and drafted descriptions for each. For example, focalism manifests in failures to consider the possibility and consequences of having a machine-dependent child surviving for years (Carnevale et al., 2006), due to a limited focus on survival, pain of loss, benefits of tracheostomy, and short-term outcomes. Third, we wrote these descriptions from an experienced parent's perspective and presented them to a pediatrician, a neonatologist, and a nurse specialized in ventilation support for pediatric patients, who gave feedback on these narratives and confirmed that these narratives reflected parents' experiences with tracheostomy decision making in real life. Fourth, we selected the two most salient issues—overestimation of the child's quality of life and underestimation of home care challenges. Lastly, we constructed narratives using structural elements that were designed to increase immersion (Shaffer, Focella, et al., 2018): 1) The narratives were in the form of first-person narrative letters; 2) The narratives told a story in a coherent and temporal manner (from what the parent thought before making the decision to what they experienced and learned after the decision); and 3) The narratives included surprises—lessons that these parents learned.

Measures

Decision. The primary outcome was participants' final decision for their hypothetical child, whether or not to place a tracheostomy.

Forecasting. We constructed eight questions to measure forecasting. The first four questions corresponded to the narratives that provided the baby's quality of life information and measured Concern for Baby's QOL, including importance of considering other outcomes beyond survival, emotional difficulty to keep your child if your child may be machine dependent forever, and likelihoods of your child having good quality of life eventually and being dependent on a machine forever. The remaining four questions corresponded to the narratives that provided family's quality of life information and measured Concern for Family's QOL, including the degree of feeling overwhelmed and exhausted regarding home care, commonness among parents of feeling overwhelmed and exhausted about home care, difficulty in getting adequate home care resources, and negative impact on family life. Participants responded to all 8 questions on a 5-point Likert Scale (1 = Not at all/None at all, 5 = Extremely/A lot).

Decisional Conflict Scale (DCS). The DCS (16 items, 0 = Strongly Agree, 4 = Strongly Disagree, Cronbach's alphas = .78–.92; O'Connor, 1995) measures the extent to which people feel a decision is not informed (e.g., "I know the benefits of each option"), value-based (e.g., "I am clear about which benefits matter most to me"), supported (e.g., "I have enough advice to make a choice"), certain (e.g., "I feel sure about what to choose"), and effective (e.g., "I am satisfied with my decision"). We included DCS because it is widely used to evaluate effectiveness of decision aids for screening and treatment decisions by assessing whether people’s feeling of uncertainty is reduced after intervention (Kryworuchko et al., 2008; Légaré et al., 2012; Stacey et al., 2014).

Social Norm Beliefs and Values Measures. We constructed seven items to measure parents’ underlying beliefs and values relevant to tracheostomy decision making. We included one question about descriptive norms (their estimate of the frequency of tracheostomy versus comfort care choices out of 100 parents) and six injunctive social norm items. Four of the six injunctive social norm items were adapted from Good-Parent Beliefs (1 = Strongly Disagree, 5 = Strongly Agree; Feudtner et al., 2015). Two measured the acceptability of comfort care through agreement with the statement that “Other people will understand that I choose comfort care for my child” (1 = Strongly Disagree, 5 = Strongly Agree) and whether comfort care was becoming more and more or less and less acceptable, or the level of acceptability had not changed. We also included one question assessing agreement with the statement that “Abortion is not acceptable under any circumstances” (1 = Strongly Disagree, 5 = Strongly Agree), because pro-life or pro-choice attitude may predict attitude towards life-sustaining techniques such as tracheostomy placement.

In addition, we included individual differences scales measuring different constructs that we hypothesized might affect parent’s tracheostomy decisions:

Medical Maximizer-Minimizer Scale (MMS). The MMS (10 items, 1 = Strongly Disagree, 7 = Strongly Agree, Cronbach’s alphas = .86–.87; Scherer et al., 2016) measures people’s attitudes towards seeking health care when dealing with medical problems, for example, “When it comes to health care, the only responsible thing to do is to actively seek medical care.” Medical maximizers prefer actively seeking health care regardless of severity of the condition while minimizers prefer watching and waiting. The MMS has demonstrated its validity to predict healthcare preferences based on patient's tendency to maximize or minimize and tracheostomy decision may be no exception. For instance, medical maximizers are more likely than minimizers to want screening (Scherer et al., 2018), choose the more active treatment option (Kang et al., 2018), and participate in care timely (Smith et al., 2018).

End-of-Life Values Scale (EOLV). The original EOLV (8 items, 0 = Not at all important, 5 = Extremely important, Cronbach's alphas = .69 and .60 for the avoidance of burden and pain/dignity subscale and longevity/family wishes/religiosity subscale respectively; Winter, 2013) measures an individual's perceptions of importance with respect to avoidance of burden and pain, desire for dignity, longevity, family wishes, and religiosity when it comes to end-of-life decision making for oneself. The items used in this study were adapted to measure parents' values of end-of-life decision making for their child. For example, the item "your wish to live as long as possible" was changed to "your wish to let you child live as long as possible." It has been argued that understanding end-of-life values is essential for realistic and effective advanced care planning (Albert et al., 2017; Billings & Bernacki, 2014; Moss & Douglas, 2018). Moreover, one study demonstrated that EOLV predicted preference for life-prolonging treatments better than a living will (Winter, 2013). Therefore, collecting decision makers' end-of-life values may help explain their decisions.

Life Orientation Test-Revised (LOT-R). The LOT-R (10 items, 6 nonfillers, 0 = I disagree a lot, 4 = I agree a lot, Cronbach's alpha = .78; Scheier, Carver, & Bridges, 1994) is used to measure how optimistic people are in general, for instance, "I'm always optimistic about my future." Research has shown that dispositional optimism predicts more positive appraisals, lower psychological distress, and more immediate risk-taking actions when encountering significant medical events (Steginga & Occhipinti, 2006; Sung et al., 2009; Zhao et al., 2015). Therefore, optimism could influence how people react to our narratives and make the tracheostomy decision.

Consideration for Future Consequences (CFC). This is a 12-item scale (1 = Extremely Uncharacteristic, 5 = Extremely Characteristic, Cronbach's alphas = .80–.86; Strathman et al., 1994) that measures "the extent to which people consider distant vs immediate consequences of potential behaviors," e.g., "I consider how things might be in the future, and try to influence those things with my day to day behavior." People with low CFC weigh short-term benefits more than long-term negative outcomes while high CFC counterparts value long-term benefits more than immediate negative outcomes (Orbell et al., 2004). As value-laden tracheostomy decisions usually entail tradeoffs between short-term and long-term outcomes, CFC is a relevant individual difference that may influence how people process the information and arrive at a decision.

Data Analysis

We used SAS software version 9.4 (SAS Institute Inc, Cary, NC) for data analysis. We first obtained descriptive statistics of participants' demographics, social norm beliefs and values, and individual differences. To test **Hypothesis 1**, we conducted a logistic regression that used condition to predict decision. To test **Hypothesis 2**, we used one-way ANOVA to compare forecasting ratings among conditions. For **Hypothesis 3**, we included condition and forecasting in the logistic regression to predict decision. For **Hypothesis 4**, we conducted a logistic regression, which included demographics, beliefs and values, individual differences, and condition as predictors and decision as the outcome variable. For **Hypothesis 5**, we used one-way ANOVA to compare decisional conflict and its subdimensions among conditions.

Results

In total, 5640 adults answered the screening questions, and 2855 met all eligibility criteria. Out of 2855 eligible participants, 2032 answered all reading comprehension questions correctly and 2013 completed the entire survey. In addition, we excluded 47 respondents based on the following criteria: 1) total time spent on survey: less than 5 minutes, and/or total time spent on the vignette: less than 10 seconds (*n* = 43); 2) implausible ages: 5 and 414 years old (*n* = 2); 3) missing data on more than 1 survey scale (*n* = 2). Final analytical sample size was 1966.

Participants' Characteristics

Demographics

The demographics of our study participants are shown in Table 2.1. The average age of the participants was 33.59, and approximately half of them were female. The participants were mostly White (78.6%), with some Black or African American (10.9%) and Asian (7.1%), and 9.6% were Hispanic. Half of them were Christian, Catholic or Baptist. Slightly more than half reported a Bachelor's degree or higher, but more than half also reported a current household income less than $60,000. Four percent were healthcare professionals with experience or expertise in life support or end-of-life decisions, and most participants did not have experience or expertise in life support decision making.

Table 2.1 Participants' Demographics (N = 1966)

Demographics	Value*
Parental status, n (%)	
Has a child age < 6 yrs	950 (48.3)
Planning pregnancy < 5 yrs†	1016 (51.7)
Gender, n (%)	
Male	991 (50.4)
Female	971 (49.4)
Transgender	4 (.2)
Age, mean (range)	33.59 (18–68)
Race, n (%)	
White	1537 (78.6)
Black or African American	213 (10.9)
Asian	139 (7.1)
Other (including Native American, multi-race, etc)	67 (3.4)
Hispanic, n (%)	188 (9.6)
Religion, n (%)	
Christian/Catholic/Baptist	998 (50.8)
Jewish	33 (1.7)
Muslim	22 (1.1)
Atheist	611 (31.1)
Other (including agnostic, Buddhism, non-religious, etc)	302 (15.4)
Education, n (%)	
Less than high school degree	4 (0.2)
High school diploma or equivalent including GED	213 (10.9)
Some college but no degree	379 (19.3)
Associate degree in college (2-year)	262 (13.4)
Bachelor's degree in college (4-year)	851 (43.4)
Master's degree	206 (10.5)
Doctoral degree	20 (1.0)
Professional degree (JD, MD)	28 (1.4)
Current household income, n (%)	
Less than $10,000	46 (2.3)
$10,000-$19,999	100 (5.1)
$20,000-$29,999	218 (11.1)
$30,000-$39,999	234 (11.9)
$40,000-$49,999	244 (12.4)
$50,000-$59,999	256 (13.0)
$60,000-$69,999	194 (9.9)
$70,000-$79,999	180 (9.2)
$80,000-$89,999	120 (6.1)
$90,000-$99,999	110 (5.6)
$100,000-$149,999	188 (9.6)
More than $150,000	76 (3.9)
Healthcare professional (experience or expertise in life support/end-of-life decisions), n (%)	79 (4.0)
Prior life support decision-making experience for family, n (%)‡	331 (16.8)

* Percentages were calculated after adjusting for missing observations.

† Among the planning pregnancy group, 654 participants self-reported having no living children when answering the previous screening question about the age of their youngest living child.

‡ Thirty-five participants reported having involved in decision making regarding the continuation of life support for their child.

Social Norm Beliefs and Values

The Social Norm Beliefs and Values Measures were intended to capture participants' beliefs and values about medical decision making and comfort care. The participants estimated that on average 58 (*SD* = 21) out of 100 parents would choose tracheostomy when facing the same decision. Moreover, they tended to strongly agree that the child's needs and quality of life should be focused on and that parents should be realistic. The participants moderately agreed that parents should do everything to prolong child's life and that other people would understand that they chose comfort care for their child (descriptive statistics see Table 2.2).

Table 2.2 Descriptive Statistics of Injunctive Social Norm Beliefs and Values Measures

Item (1 = Strongly Disagree, 5 = Strongly Agree)	Mean (*SD*)
1. Parents should do everything to prolong their child's life.	3.24 (1.08)
2. Parents should focus on their child's quality of life.	4.47 (.69)
3. Parents should put their child's needs above his or her own when making medical care decisions.	4.23 (.89)
4. Parents should keep a realistic outlook.	4.51 (.67)
5. Other people will understand that I choose comfort care for my child.	3.45 (1.05)

In addition, the participants were asked to indicate their beliefs about the trend of comfort care's acceptability. The majority of the participants believed that comfort care was becoming more and more acceptable (*n* = 895) or the level of acceptability had not changed (*n* = 898) while only 173 participants believed that comfort care was becoming less and less acceptable. On average the participants somewhat disagreed that abortion was not acceptable under any circumstances (*M* = 2.05, *SD* = 1.32).

Individual Differences

Mean (*SD*) MMS score was 3.96 (1.12). Mean (*SD*) LOT-R (optimism) score was 2.47 (1.02). Mean (*SD*) CFC score was 3.71 (.68). The average importance rating of avoidance of burden and pain/dignity when making medical decisions for one's child was 3.46 (*SD* = 1.07) and the average importance rating of longevity/family wishes/religiosity was 2.54 (*SD* = 1.15).

Effects of Narratives on Decision

As hypothesized, viewing narratives of long-term implications of tracheostomy had an impact on decision (**Hypothesis 1**). While about 47% of the participants in the control condition (*n* = 505) chose tracheostomy, only 22% in the Baby QOL (*n* = 480), 38% in the Family QOL (*n* = 495), and 24% in the Baby QOL + Family QOL (*n* = 486) conditions did so (Figure 2.2). To quantify the effect sizes, we compared decisions of each experimental condition to those of control using a logistic regression. The odds that the participants in the Baby QOL + Family QOL, Baby QOL, and Family QOL conditions chose to place a tracheostomy were 64%, 68%, and 30% lower than those of the control (Table 2.3).

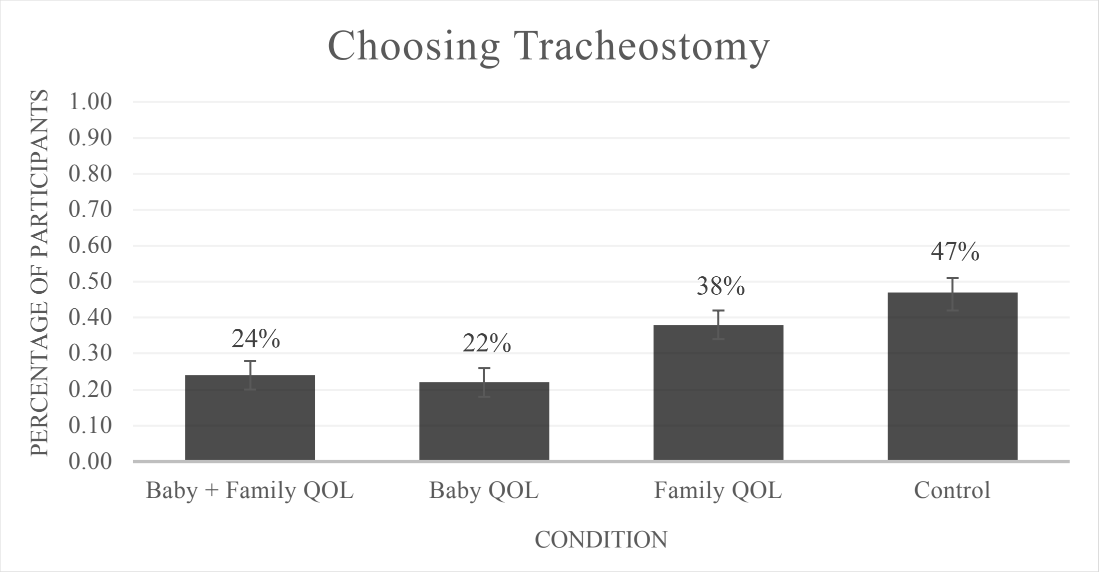

Figure 2.2 Percentages of Participants Who Chose to Place a Tracheostomy

Table 2.3 Logistic Regression Predicting Choosing Tracheostomy from Condition

Comparison	Odds Ratio	95% CI	*p*
Baby QOL + Family QOL vs Control	.36	[.27, .47]	< .001
Baby QOL vs Control	.32	[.24, .42]	< .001
Family QOL vs Control	.70	[.54, .90]	.005

In addition, we observed that while the effects of viewing both types of narratives and the Baby QOL narratives were similar, they seemed larger than that of viewing the Family QOL narratives. Hence, we compared decisions of the Baby QOL + Family QOL and Baby QOL conditions to those of the Family QOL condition. The odds that the participants in the Baby QOL + Family QOL and Baby QOL conditions chose to place a tracheostomy were 49% and 54% lower than those of the Family QOL condition (*OR* = .51 and .46 respectively, 95% CI [.39, .68] and [.35, .61] respectively, $p < .001$). Viewing both types of narratives or the Baby QOL narratives reduced the tendency to choose tracheostomy more than the Family QOL narratives.

Effects of Narratives on Forecasting

As shown in Table 2.4, consistent with **Hypothesis 2**, narratives significantly changed the participants' forecasting regarding the baby's and family's potential quality of life. The control condition tended to yield the most positive forecasts while receiving both types of narratives tended to make the participants the most pessimistic. Moreover, the Baby QOL narratives tended to increase negative forecasts on Concern for Baby's QOL items the most and the Family QOL narratives tended to increase negative forecasts on Concern for Family's QOL items the most (statistics see Table 2.4).

Table 2.4 Perceptions of Baby's and Family's Potential Quality of Life across Conditions

Item (1 = None/Not at all, 5 = A lot/Extremely)	Baby QOL + Family QOL	Baby QOL	Family QOL	Control	*F*	*p*	η_p^2
	M (*SD*)	*M* (*SD*)	*M* (*SD*)	*M* (*SD*)			
Concern for Baby QOL							
1.Importance of considering other outcomes beyond survival	4.63 (.73)	4.64 (.71)	4.51 (.82)	4.52 (.74)	3.95	.008	.006
2.Emotional difficulty to keep your child if your child may be machine dependent forever	4.62 (.71)	4.47 (.90)	4.57 (.80)	4.38 (1.01)	7.43	<.001	.01
3.Likelihood of your child having good quality of life eventually	2.00 (.95)	2.07 (1.00)	2.43 (1.21)	2.68 (1.29)	39.83	<.001	.06
4.Likelihood of your child being on machine forever	4.49 (.82)	4.46 (.84)	4.26 (.99)	4.09 (1.04)	20.40	<.001	.03
Concern for Family QOL							
5.Feeling overwhelmed and exhausted about home care	4.74 (.57)	4.62 (.67)	4.74 (.58)	4.50 (.77)	15.17	<.001	.02
6.Common to feel overwhelmed and exhausted about home care	4.80 (.53)	4.75 (.54)	4.85 (.44)	4.69 (.63)	7.77	<.001	.01
7.Difficult to get adequate resources for home care	4.53 (.76)	4.44 (.82)	4.55 (.70)	4.36 (.89)	5.90	<.001	.009
8.Negative impact on family life	4.34 (.81)	4.20 (.92)	4.26 (.90)	3.97 (1.06)	14.74	<.001	.02

Note: 1) η_p^2 represents effect size of the ANOVA test. In general, .01, .06, .14 indicate small, medium, large effect sizes respectively (Cohen, 1988). 2) Mean differences greater than approximately .15 were significant at 5% level (approximately .09 for items 5 and 6).

Effects of Narratives on Decision (Controlling for Forecasting)

The observed changes in the participants' forecasting beliefs were significantly associated with their decisions, and the effects of narratives on decision reduced after taking forecasting into account (**Hypothesis 3**). The following forecasting tendencies were associated with lower odds of choosing tracheostomy: 1) more perceived importance of considering other outcomes beyond survival; 2) more perceived emotional difficulty to keep the child if they may be machine dependent forever; 3) more pessimistic judgments about the child's future quality of life and chance to get off the ventilator; 4) perception that it is less common to feel overwhelmed and exhausted about home care; and 5) more perceived negative impact on family. After controlling for variations in forecasting, the odds that the participants in the Baby QOL condition chose to place a tracheostomy were significantly lower (44%) than those of the control. However, the Baby QOL + Family QOL and Family QOL conditions were not statistically different in their tendency to choose tracheostomy from the control condition (statistics see Table 2.5).

Table 2.5 Logistic Regression Predicting Choosing Tracheostomy from Condition and Concern for Baby's and Family's QOL

Predictor	Odds Ratio	95% CI	*p*
Intercept	.54	NA	.45
Baby QOL + Family QOL vs Control	.84	[.56, 1.26]	.39
Baby QOL vs Control	.56	[.37, .84]	.005
Family QOL vs Control	.89	[.60, 1.31]	.54
Importance of considering other outcomes beyond survival	.51	[.42, .62]	< .001
Emotional difficulty to keep your child if your child may be machine dependent forever	.78	[.65, .95]	.01
Likelihood of your child having good quality of life eventually	5.75	[4.78, 6.92]	< .001
Likelihood of your child being on machine forever	.61	[.52, .71]	< .001
Feeling overwhelmed and exhausted about home care	1.23	[.92, 1.63]	.16
Common to feel overwhelmed and exhausted about home care	2.00	[1.45, 2.75]	< .001
Difficult to get adequate resources for home care	.84	[.69, 1.03]	.09
Negative impact on family life	.69	[.58, .82]	< .001

Note: The intercept is not interpretable because the forecasting scores start at 1.

Effects of Narratives on Decision (Controlling for Demographics, Beliefs and Values, and Individual Differences)

To demonstrate the robust effect of narratives on decision (**Hypothesis 4**), we conducted a logistic regression analysis to examine whether the effects of narratives on decision still existed after controlling for variations in demographics, beliefs and values, and individual differences (Table 2.6). After controlling for individual characteristics variables, the odds of choosing tracheostomy were 62% lower for the Baby QOL + Family QOL condition compared to those of the control. The odds of choosing tracheostomy were 75% lower for the Baby QOL condition than those in the control condition. Fewer participants in the Family QOL condition chose tracheostomy compared to the control, although the difference was not statistically significant.

The section below explores and describes how variations in demographics, beliefs and values, and individual differences were associated with tracheostomy decisions.

Demographics

We found that women (compared to men), Asian (compared to White), and healthcare professionals who had expertise or experience in life support or end-of-life decisions (compared to non-healthcare professionals) were more likely to choose tracheostomy. Other demographics did not significantly predict choice of tracheostomy.

Beliefs and Values

The following beliefs and values predicted preference to choose tracheostomy: 1) higher estimate of how many parents would choose tracheostomy; 2) more agreement with the statements "Parents should do everything to prolong their child's life" and "Parents should put their child's needs above his or her own when making medical care decisions." On the contrary, more agreement with statements "Parents should focus on their child's quality of life," "Parents should keep a realistic outlook," and "Other people will understand that I choose comfort care for my child" predicted lower odds of choosing tracheostomy. Attitudes towards abortion and the trend of comfort care's acceptability did not significantly predict choice of tracheostomy.

Individual Differences

We found that the participants who were more medically maximizing (i.e., pro-active in seeking healthcare resources) were more likely to choose tracheostomy. As for end-of-life values, more emphasis on "your religious or spiritual beliefs," "the wishes of other family members regarding your child's care," and "your wish to let your child live as long as possible" when making pediatric medical decisions predicted higher odds of choosing tracheostomy. On the other hand, more emphasis on "your wish to let your child be spared pain," "your wish to avoid being dependent on others with your child's condition," "your wish to avoid burdening family and friends emotionally/financially with your child's condition," and "your wish to let your child have a dignified death" predicted lower odds of choosing tracheostomy. However, optimism and consideration of future consequences did not predict decision.

Table 2.6 Logistic Regression Predicting Choosing Tracheostomy from Condition, Demographics, Beliefs and Values, Individual Differences

Predictor	Odds Ratio	95% CI	*p*
Intercept	.02	NA	< .001
Baby QOL + Family QOL vs Control	.38	[.25, .59]	< .001
Baby QOL vs Control	.25	[.16, .39]	< .001
Family QOL vs Control	.70	[.46, 1.08]	.11
Demographics			
Age	1.00	[.98, 1.02]	.79
Women vs Men	1.50	[1.09, 2.06]	.01
Black vs White	.95	[.57, 1.56]	.83
Asian vs White	1.91	[1.06, 3.44]	.03
Other vs White	1.71	[.75, 3.91]	.20
Hispanic vs Non-Hispanic	.77	[.44, 1.36]	.37
Bachelor's degree or higher vs Associate degree or lower	1.02	[.73, 1.42]	.90
Income ≥ $60K vs Income < $60K	.83	[.59, 1.16]	.26
Professional vs Non-professional	3.39	[1.52, 7.54]	.003
Life support decision-making experience vs No experience	1.23	[.81, 1.87]	.34
Beliefs and Values			
Estimate of how many other parents would choose tracheostomy when facing the same decision	1.05	[1.04, 1.06]	< .001

Predictor	Odds Ratio	95% CI	*p*
1. Parents should do everything to prolong their child's life.	3.38	[2.73, 4.20]	< .001
2. Parents should focus on their child's quality of life.	.36	[.27, .48]	< .001
3. Parents should put their child's needs above his or her own when making medical care decisions.	1.53	[1.20, 1.94]	< .001
4. Parents should keep a realistic outlook.	.69	[.53, .90]	.006
5. Other people will understand that I choose comfort care for my child.	.82	[.69, .98]	.02
Comfort care is becoming less and less acceptable vs more and more acceptable	.60	[.32, 1.11]	.10
The level of acceptability of comfort care has not changed vs more and more acceptable	.82	[.59, 1.15]	.25
Abortion is not acceptable under any circumstances.	1.13	[.99, 1.30]	.06
Individual Differences			
Medical Maximizer-Minimizer	1.53	[1.29, 1.82]	< .001
End-of-Life Values (Avoidance of burden and pain/dignity)	.43	[.36, .52]	< .001
End-of-Life Values (Longevity/family wishes/religiosity)	2.14	[1.76, 2.59]	< .001
Optimism (LOT-R)	.97	[.81, 1.15]	.70
Consideration of Future Consequences	1.14	[.88, 1.48]	.33

Note: We explored plausible interactions of demographic variables. We found no significant interactions (i.e., between age and gender, race and gender, education and gender, income and gender, profession and gender) and no significant impact on the effects of narratives compared to the model in which only main effects were included. Therefore, we presented the results of the model without interactions.

Effects of Narratives on Decisional Conflict

Narratives did not significantly change overall decisional conflict **(Hypothesis 5)**. Specifically, narratives did not change how much the participants felt informed about the alternatives, felt clear about personal values, supported in decision making, or uncertain about the decision. The participants also considered their decision similarly effective (*ps* >.05, statistics see Table 2.7).

Table 2.7 Decisional Conflict across Conditions

Variable (0 = Strongly Agree, 4 = Strongly Disagree, Range: [0,100])	Baby QOL + Family QOL *M* (*SD*)	Baby QOL *M* (*SD*)	Family QOL *M* (*SD*)	Control *M* (*SD*)	*F*	*p*
Total	21.97 (14.81)	22.33 (14.09)	21.88 (14.05)	22.43 (14.27)	.18	.91
Informed Decision	13.60 (15.40)	13.59 (13.08)	13.80 (13.52)	14.47 (13.71)	.44	.73
Value Clarity	14.78 (17.54)	15.55 (16.14)	16.04 (17.31)	16.47 (16.19)	.92	.43
Support	21.06 (18.14)	21.68 (17.73)	21.11 (16.55)	21.59 (17.73)	.17	.92
Uncertainty	38.45 (23.91)	39.04 (23.56)	36.89 (23.82)	37.76 (24.84)	.73	.54
Decision Effectiveness	21.95 (17.00)	21.95 (17.15)	21.63 (17.39)	22.01 (16.78)	.05	.99

Discussion

We theorized that forecasting errors would occur in tracheostomy decision making and tested the effects of targeted narratives addressing these biases to inform decision making. In our hypothetical tracheostomy scenario, both sets of narratives decreased the participants' tendency to choose tracheostomy, although narratives about baby's quality of life produced a larger effect than narratives about home care challenges. Additionally, our narratives increased pessimistic forecasting about quality of life of the baby and family. In particular, as our design intended, narratives about baby's quality of life mostly increased concern for baby's long-term outcomes while narratives about family's quality of increased concern for family's long-term outcomes. Forecasting beliefs were strongly associated with the participants' decisions.

These findings first demonstrate that forecasting errors exist in this type of pediatric tracheostomy decision making where prognosis is poor and that they potentially impact final decisions. The participants without receiving our targeted narratives held more optimistic views about specific future outcomes and therefore tended to choose tracheostomy compared to those who were informed by our narratives. This discrepancy in beliefs and behavioral intention suggests that a lack of knowledge of what long-term implications entail may place parents at risk of limiting the focus to survival and overestimating quality of life later. Therefore, it is important to provide relevant information for addressing forecasting errors in real-life tracheostomy decision making.

We also demonstrate that our narratives impacted decisions, possibly through changing forecasting. According to the Narrative Immersion Model (Shaffer, Focella, et al., 2018), our narratives provided information about possible experiences, outcomes, and decision making learning lessons in two specific domains, which the participants assimilated for making more realistic judgments and decisions accordingly. Although we could not test formal mediation because this study was cross-sectional and measured decision before forecasting, the results were consistent with our theory and a mediational process: Viewing narratives was associated with less positive forecasting, and less positive forecasting was associated with less interest in tracheostomy.

Our narratives regarding baby's quality of life had a larger effect on tracheostomy decision making than those of family's quality of life. There are several possible explanations. One is that forecasting errors about home care burden may be smaller than those about the baby's future. It may be easier for parents to envision logistic challenges than a child with life-limiting illness and therefore narratives about family quality of life are not entirely new pieces of information. Alternatively, parents may not deem home care as determining as the child's quality of life in tracheostomy decisions. This could be explained by the literature on good-parent belief

(Feudtner et al., 2015; Lotz et al., 2017; October et al., 2014). As the participants in our survey gave higher ratings to valuing quality of life rather than length of life, knowing that tracheostomy may not improve long-term quality of life minimizes potentially unrealistic expectations about future quality of life and therefore influences the final decision. Moreover, parents believe that they should advocate for the child and not give up because of their own feelings of burden or logistic difficulties and caregivers usually improve on their caring skills and adapt to these home care challenges (Nageswaran et al., 2018). It is also possible that our narratives of baby's quality of life were more vivid and engaging than the other set of narratives.

We did not find that our Baby QOL and Family QOL narratives impacted decisional conflict immediately after decision making. Our narratives did not either increase 1) the participants' subjective knowledge of options (tracheostomy and no tracheostomy: comfort care); 2) their understanding of own values regarding options; 3) their perceived support from others; 4) their certainty in decision; or 5) their perceived decision effectiveness. For decisions without a clear best option, it may be hard for parents to appreciate the value of narratives in such a short time, especially if they perceive the narratives contradictory to their prior beliefs. This finding is consistent with the breast cancer decision aid study (Osaka & Nakayama, 2017), which shows that narratives do not reduce decisional conflict that is measured after decision making and before outcomes are known.

Our research suggests that this type of narrative-based intervention strategy may be valuable in other pediatric health decisions where forecasting errors are common and accurately understanding future experiences is important for making satisfying and informed decisions. For instance, it may be relevant in decisions of parents regarding dependence on technology or life-prolonging treatments for critically ill children. When making gastric feeding tube placement decisions for neurologically-impaired children, parents may underestimate challenges in care (Mahant et al., 2011; Nelson & Mahant, 2014). Parents considering whether to continue chemotherapy for their child with advanced cancer and little chance of cure tend to keep high hopes of cure even at the cost of quality of life (Tomlinson et al., 2011) and may later find the decision unsatisfying. For parents of children with trisomy 13 or 18 considering different types and levels of intervention including palliative care, many reported no regret with their decisions, while some struggled with caregiving responsibilities (Janvier et al., 2012; Lantos, 2016). Incorporating a narrative based intervention strategy may help reduce forecasting errors and decisional regret.

The study had some limitations that may affect how the results can be interpreted and generalized to real-world applications. First, the decision scenario was simplified with only two choices of tracheostomy or no tracheostomy and concise information. It also only presented a case of very poor prognosis. However, real-life pediatric tracheostomy decisions could involve different kinds of prognosis and options (e.g., waiting or trying other treatments) with more complicated informational input. This study demonstrated that the participants made different decisions and forecasts when they were informed about challenges in the situation where reasonable recovery was unlikely. In clinical settings, doctors should individualize their counseling and consider whether these narratives apply to the specific situation. Second, the study contained a hypothetical scenario and the participants were not making real decisions for their child. It is possible that parents who actually need to make a tracheostomy decision for their critically ill child may perceive the situation and use narratives differently for their decision making. Third, in the study, the decision was made by a respondent in isolation, whereas often in the clinical setting a parent would confer with other relevant people, such as their partner, other family members, spiritual leaders, and clinicians. Narratives may have more or less impact on decision making when two parents or together with other relevant people jointly make the decision. Nonetheless, our study's value lies in showing that narratives have a potential to influence parents' forecasting and decisions. Future research could further develop these narratives materials as an intervention and explore the effects and acceptability of these narratives on parents who are making actual tracheostomy decisions. Lastly, we are not able to conclude that narratives about home care challenges are always less effective than narratives about child's quality of life for tracheostomy decision making. Regardless, narratives about home care challenges may provide valuable information for parents who have not thought of these issues.

Our research demonstrates that narratives illustrating potential long-term implications of tracheostomy on long-term quality of life have the potential to influence forecasting and decisions. This study has practical implications for providers and parents who are involved in pediatric tracheostomy decision making and other similar types of high-stakes decision where patients or surrogate decision makers are at risk of making inaccurate predictions or having unrealistic expectations for informed decision making. Providing narratives from other parents who have made the decision could be an effective and feasible way to support parents in making an informed decision.

References

Albert, S. M., Lunney, J. R., Ye, L., Boudreau, R., Ives, D., Satterfield, S., Kaplan, C. M., Waters, T., Ayonayon, H. N., Rubin, S. M., Newman, A. B., & Harris, T. (2017). Are preferences for aggressive medical treatment associated with healthcare utilization in the very old? *Journal of Palliative Medicine*, *20*(6), 618–624. https://doi.org/10.1089/jpm.2016.0284

Allen, K. A. (2014). Parental decision-making for medically complex infants and children: An integrated literature review. *International Journal of Nursing Studies*, *51*(9), 1289–1304. https://doi.org/10.1016/j.ijnurstu.2014.02.003

Angott, A. M., Comerford, D. A., & Ubel, P. A. (2013). Imagining life with an ostomy: Does a video intervention improve quality-of-life predictions for a medical condition that may elicit disgust? *Patient Education and Counseling*, *91*(1), 113–119. https://doi.org/10.1016/j.pec.2012.10.015

Bekker, H. L., Winterbottom, A. E., Butow, P., Dillard, A. J., Feldman-Stewart, D., Fowler, F. J., Jibaja-Weiss, M. L., Shaffer, V. A., & Volk, R. J. (2013). Do personal stories make patient decision aids more effective? A critical review of theory and evidence. *BMC Medical Informatics and Decision Making*, *13*(2), Article S9. https://doi.org/10.1186/1472-6947-13-S2-S9

Betsch, C., Ulshöfer, C., Renkewitz, F., & Betsch, T. (2011). The influence of narrative v. statistical information on perceiving vaccination risks. *Medical Decision Making*, *31*(5), 742–753. https://doi.org/10.1177/0272989X11400419

Billings, J. A., & Bernacki, R. (2014). Strategic targeting of advance care planning interventions: The goldilocks phenomenon. *JAMA Internal Medicine*, *174*(4), 620–624. https://doi.org/10.1001/jamainternmed.2013.14384

Braddock, K., & Dillard, J. P. (2016). Meta-analytic evidence for the persuasive effect of narratives on beliefs, attitudes, intentions, and behaviors. *Communication Monographs*, *83*(4), 446–467. https://doi.org/10.1080/03637751.2015.1128555

Carnevale, F. A., Alexander, E., Davis, M., Rennick, J., & Troini, R. (2006). Daily living with distress and enrichment: The moral experience of families with ventilator-assisted children at home. *Pediatrics*, *117*(1), e48–e60. https://doi.org/10.1542/peds.2005-0789

Carnevale, F. A., Benedetti, M., Bonaldi, A., Bravi, E., Trabucco, G., & Biban, P. (2011). Understanding the private worlds of physicians, nurses, and parents: A study of life-sustaining treatment decisions in Italian paediatric critical care. *Journal of Child Health Care*, *15*(4), 334–349. https://doi.org/10.1177/1367493511420183

Cohen, J. (1988). *Statistical power analysis for the behavioral sciences* (2nd ed.). Routledge. https://doi.org/10.4324/9780203771587

De Graaf, A., Sanders, J., & Hoeken, H. (2016). Characteristics of narrative interventions and health effects: A review of the content, form, and context of narratives in health-related narrative persuasion research. *Review of Communication Research*, *4*(1), 88–131. https://doi.org/10.12840/issn.2255-4165.2016.04.01.011

De Wit, J. B. F., Das, E., & Vet, R. (2008). What works best: Objective statistics or a personal testimonial? An assessment of the persuasive effects of different types of message evidence on risk perception. *Health Psychology*, *27*(1), 110–115. https://doi.org/10.1037/0278-6133.27.1.110

Demke, J., Bassim, M., Patel, M. R., Dean, S., Rahbar, R., van Aalst, J. A., & Drake, A. (2008). Parental perceptions and morbidity: Tracheostomy and Pierre Robin sequence. *International Journal of Pediatric Otorhinolaryngology*, *72*(10), 1509–1516. https://doi.org/10.1016/j.ijporl.2008.07.002

Dillard, A., Fagerlin, A., Cin, S. D., Zikmund-Fisher, B. J., & Ubel, P. A. (2010). Narratives that address affective forecasting errors reduce perceived barriers to colorectal cancer screening. *Social Science & Medicine*, *71*(1), 45–52. https://doi.org/10.1016/j.socscimed.2010.02.038

Entwistle, V. A., France, E. F., Wyke, S., Jepson, R., Hunt, K., Ziebland, S., & Thompson, A. (2011). How information about other people's personal experiences can help with healthcare decision-making: A qualitative study. *Patient Education and Counseling*, *85*(3), e291–e298. https://doi.org/10.1016/j.pec.2011.05.014

Fagerlin, A., Wang, C., & Ubel, P. A. (2005). Reducing the influence of anecdotal reasoning on people's health care decisions: Is a picture worth a thousand statistics? *Medical Decision Making*, *25*(4), 398–405. https://doi.org/10.1177/0272989X05278931

Falzon, C., Radel, R., Cantor, A., & d'Arripe-Longueville, F. (2015). Understanding narrative effects in physical activity promotion: The influence of breast cancer survivor testimony on exercise beliefs, self-efficacy, and intention in breast cancer patients. *Supportive Care in Cancer*, *23*(3), 761–768. https://doi.org/10.1007/s00520-014-2422-x

Feldman, G., & Albarracín, D. (2017). Norm theory and the action-effect: The role of social norms in regret following action and inaction. *Journal of Experimental Social Psychology*, *69*, 111–120. https://doi.org/10.1016/j.jesp.2016.07.009

Feudtner, C., Walter, J. K., Faerber, J. A., Hill, D. L., Carroll, K. W., Mollen, C. J., Miller, V. A., Morrison, W. E., Munson, D., Kang, T. I., & Hinds, P. S. (2015). Good-parent beliefs of parents of seriously ill children. *JAMA Pediatrics*, *169*(1), 39–47. https://doi.org/10.1001/jamapediatrics.2014.2341

Flynn, A. P., Carter, B., Bray, L., & Donne, A. J. (2013). Parents' experiences and views of caring for a child with a tracheostomy: A literature review. *International Journal of Pediatric Otorhinolaryngology*, *77*(10), 1630–1634. https://doi.org/10.1016/j.ijporl.2013.07.020

Garrubba, M., Turner, T., & Grieveson, C. (2009). Multidisciplinary care for tracheostomy patients: A systematic review. *Critical Care*, *13*(6), Article R177. https://doi.org/10.1186/cc8159

Gilbert, D. T., Pinel, E. C., Wilson, T. D., Wheatley, T. P., & Blumberg, S. J. (1998). Immune neglect: A source of durability bias in affective forecasting. *Journal of Personality and Social Psychology*, *75*(3), 617–638. https://doi.org/10.1037/0022-3514.75.3.617

Gilovich, T., Griffin, D., & Kahneman, D. (Eds.). (2002). *Heuristics and biases: The psychology of intuitive judgment*. Cambridge University Press. https://doi.org/10.1017/CBO9780511808098

Gilovich, T., & Medvec, V. H. (1994). The temporal pattern to the experience of regret. *Journal of Personality and Social Psychology*, *67*(3), 357–365. https://doi.org/10.1037/0022-3514.67.3.357

Halpern, J., & Arnold, R. M. (2008). Affective forecasting: An unrecognized challenge in making serious health decisions. *Journal of General Internal Medicine*, *23*(10), 1708–1712. https://doi.org/10.1007/s11606-008-0719-5

Hebert, L. M., Watson, A. C., Madrigal, V., & October, T. W. (2017). Discussing benefits and risks of tracheostomy: What physicians actually say. *Pediatric Critical Care Medicine*, *18*(12), e592–e597. https://doi.org/10.1097/PCC.0000000000001341

Hopkins, C., Whetstone, S., Foster, T., Blaney, S., & Morrison, G. (2009). The impact of paediatric tracheostomy on both patient and parent. *International Journal of Pediatric Otorhinolaryngology*, *73*(1), 15–20. https://doi.org/10.1016/j.ijporl.2008.09.010

Janvier, A., Farlow, B., & Wilfond, B. S. (2012). The experience of families with children with trisomy 13 and 18 in social networks. *Pediatrics*, *130*(2), 293–298. https://doi.org/10.1542/peds.2012-0151

Kang, S. K., Scherer, L. D., Megibow, A. J., Higuita, L. J., Kim, N., Braithwaite, R. S., & Fagerlin, A. (2018). A randomized study of patient risk perception for incidental renal findings on diagnostic imaging tests. *American Journal of Roentgenology*, *210*(2), 369–375. https://doi.org/10.2214/AJR.17.18485

Kaufman, G. F., & Libby, L. K. (2012). Changing beliefs and behavior through experience-taking. *Journal of Personality and Social Psychology*, *103*(1), 1–19. https://doi.org/10.1037/a0027525

Kruger, J., & Burrus, J. (2004). Egocentrism and focalism in unrealistic optimism (and pessimism). *Journal of Experimental Social Psychology*, *40*(3), 332–340. https://doi.org/10.1016/j.jesp.2003.06.002

Kryworuchko, J., Stacey, D., Bennett, C., & Graham, I. D. (2008). Appraisal of primary outcome measures used in trials of patient decision support. *Patient Education and Counseling*, *73*(3), 497–503. https://doi.org/10.1016/j.pec.2008.07.011

Kunda, Z. (1990). The case for motivated reasoning. *Psychological Bulletin*, *108*(3), 480–498. https://doi.org/10.1037/0033-2909.108.3.480

Lantos, J. D. (2016). Trisomy 13 and 18—treatment decisions in a stable gray zone. *JAMA*, *316*(4), 396–398. https://doi.org/10.1001/jama.2016.9470

Légaré, F., LeBlanc, A., Robitaille, H., & Turcotte, S. (2012). The decisional conflict scale: Moving from the individual to the dyad level. *Zeitschrift Für Evidenz, Fortbildung Und Qualität Im Gesundheitswesen*, *106*(4), 247–252. https://doi.org/10.1016/j.zefq.2012.02.021

Lemal, M., & Van den Bulck, J. (2010). Testing the effectiveness of a skin cancer narrative in promoting positive health behavior: A pilot study. *Preventive Medicine*, *51*(2), 178–181. https://doi.org/10.1016/j.ypmed.2010.04.019

Liberman, N., Sagristano, M. D., & Trope, Y. (2002). The effect of temporal distance on level of mental construal. *Journal of Experimental Social Psychology*, *38*(6), 523–534. https://doi.org/10.1016/S0022-1031(02)00535-8

Litman, L., Robinson, J., & Abberbock, T. (2017). TurkPrime.com: A versatile crowdsourcing data acquisition platform for the behavioral sciences. *Behavior Research Methods*, *49*(2), 433–442. https://doi.org/10.3758/s13428-016-0727-z

Lotz, J. D., Daxer, M., Jox, R. J., Borasio, G. D., & Führer, M. (2017). “Hope for the best, prepare for the worst”: A qualitative interview study on parents’ needs and fears in pediatric advance care planning. *Palliative Medicine*, *31*(8), 764–771. https://doi.org/10.1177/0269216316679913

Mahant, S., Jovcevska, V., & Cohen, E. (2011). Decision-making around gastrostomy-feeding in children with neurologic disabilities. *Pediatrics*, *127*(6), e1471–e1481. https://doi.org/10.1542/peds.2010-3007

McCormick, M. E., Ward, E., Roberson, D. W., Shah, R. K., Stachler, R. J., & Brenner, M. J. (2015). Life after tracheostomy: Patient and family perspectives on teaching, transitions, and multidisciplinary teams. *Otolaryngology–Head and Neck Surgery*, *153*(6), 914–920. https://doi.org/10.1177/0194599815599525

Michelson, K. N., Koogler, T., Sullivan, C., del Pilar Ortega, M., Hall, E., & Frader, J. (2009). Parental views on withdrawing life-sustaining therapies in critically ill children. *Archives of Pediatrics & Adolescent Medicine*, *163*(11), 986–992. https://doi.org/10.1001/archpediatrics.2009.180

Moss, K. O., & Douglas, S. L. (2018). Family caregiver satisfaction with end-of-life care following advanced cancer. *Oncology Nursing News*, *12*(2), Article 32.

Nageswaran, S., Golden, S. L., Gower, W. A., & King, N. M. P. (2018). Caregiver perceptions about their decision to pursue tracheostomy for children with medical complexity. *The Journal of Pediatrics*, *203*, 354–360.e1. https://doi.org/10.1016/j.jpeds.2018.07.045

Nelson, J. E., Kinjo, K., Meier, D. E., Ahmad, K., & Morrison, R. S. (2005). When critical illness becomes chronic: Informational needs of patients and families. *Journal of Critical Care*, *20*(1), 79–89. https://doi.org/10.1016/j.jcrc.2004.11.003

Nelson, J. E., Mercado, A. F., Camhi, S. L., Tandon, N., Wallenstein, S., August, G. I., & Morrison, R. S. (2007). Communication about chronic critical illness. *Archives of Internal Medicine*, *167*(22), 2509–2515. https://doi.org/10.1001/archinte.167.22.2509

Nelson, K. E., & Mahant, S. (2014). Shared decision-making about assistive technology for the child with severe neurologic impairment. *Pediatric Clinics of North America*, *61*(4), 641–652. https://doi.org/10.1016/j.pcl.2014.04.001

O'Connor, A. M. (1995). Validation of a decisional conflict scale. *Medical Decision Making*, *15*(1), 25–30. https://doi.org/10.1177/0272989X9501500105

October, T. W., Fisher, K. R., Feudtner, C., & Hinds, P. S. (2014). The parent perspective: "Being a good parent" when making critical decisions in the PICU. *Pediatric Critical Care Medicine*, *15*(4), 291–298. https://doi.org/10.1097/PCC.0000000000000076

October, T. W., Jones, A. H., Greenlick Michals, H., Hebert, L. M., Jiang, J., & Wang, J. (2020). Parental conflict, regret, and short-term impact on quality of life in tracheostomy decision-making. *Pediatric Critical Care Medicine*, *21*(2), 136–142. https://doi.org/10.1097/PCC.0000000000002109

Orbell, S., Perugini, M., & Rakow, T. (2004). Individual differences in sensitivity to health communications: Consideration of future consequences. *Health Psychology*, *23*(4), 388–396. https://doi.org/10.1037/0278-6133.23.4.388

Osaka, W., & Nakayama, K. (2017). Effect of a decision aid with patient narratives in reducing decisional conflict in choice for surgery among early-stage breast cancer patients: A three-arm randomized controlled trial. *Patient Education and Counseling*, *100*(3), 550–562. https://doi.org/10.1016/j.pec.2016.09.011

Ritov, I., & Baron, J. (1994). Judgements of compensation for misfortune: The role of expectation. *European Journal of Social Psychology*, *24*(5), 525–539. https://doi.org/10.1002/ejsp.2420240502

Scheier, M. F., Carver, C. S., & Bridges, M. W. (1994). Distinguishing optimism from neuroticism (and trait anxiety, self-mastery, and self-esteem): A reevaluation of the Life Orientation Test. *Journal of Personality and Social Psychology*, *67*(6), 1063–1078. https://doi.org/10.1037/0022-3514.67.6.1063

Scherer, L. D., Caverly, T. J., Burke, J., Zikmund-Fisher, B. J., Kullgren, J. T., Steinley, D., McCarthy, D. M., Roney, M., & Fagerlin, A. (2016). Development of the Medical Maximizer-Minimizer Scale. *Health Psychology*, *35*(11), 1276–1287. https://doi.org/10.1037/hea0000417

Scherer, L. D., Kullgren, J. T., Caverly, T., Scherer, A. M., Shaffer, V. A., Fagerlin, A., & Zikmund-Fisher, B. J. (2018). Medical maximizing-minimizing preferences predict responses to information about prostate-specific antigen screening. *Medical Decision Making*, *38*(6), 708–718. https://doi.org/10.1177/0272989X18782199

Schkade, D. A., & Kahneman, D. (1998). Does living in california make people happy? A focusing illusion in judgments of life satisfaction. *Psychological Science*, *9*(5), 340–346. https://doi.org/10.1111/1467-9280.00066

Shaffer, V. A., Focella, E. S., Hathaway, A., Scherer, L. D., & Zikmund-Fisher, B. J. (2018). On the usefulness of narratives: An interdisciplinary review and theoretical model. *Annals of Behavioral Medicine*, *52*(5), 429–442. https://doi.org/10.1093/abm/kax008

Shaffer, V. A., Focella, E. S., Scherer, L. D., & Zikmund-Fisher, B. J. (2016). Debiasing affective forecasting errors with targeted, but not representative, experience narratives. *Patient Education and Counseling*, *99*(10), 1611–1619. https://doi.org/10.1016/j.pec.2016.04.004

Shaffer, V. A., Hulsey, L., & Zikmund-Fisher, B. J. (2013). The effects of process-focused versus experience-focused narratives in a breast cancer treatment decision task. *Patient Education and Counseling*, *93*(2), 255–264. https://doi.org/10.1016/j.pec.2013.07.013

Shaffer, V. A., Scherer, L. D., Focella, E. S., Hinnant, A., Len-Ríos, M. E., & Zikmund-Fisher, B. J. (2018). What is the story with narratives? How using narratives in journalism changes health behavior. *Health Communication*, *33*(9), 1151–1157. https://doi.org/10.1080/10410236.2017.1333562

Shaffer, V. A., & Zikmund-Fisher, B. J. (2013). All stories are not alike: A purpose-, content-, and valence-based taxonomy of patient narratives in decision aids. *Medical Decision Making*, *33*(1), 4–13. https://doi.org/10.1177/0272989X12463266

Smith, K. T., Monti, D., Mir, N., Peters, E., Tipirneni, R., & Politi, M. C. (2018). Access is necessary but not sufficient: Factors influencing delay and avoidance of health care services. *MDM Policy & Practice*, *3*(1), Article 238146831876029. https://doi.org/10.1177/2381468318760298

Stacey, D., Légaré, F., Col, N. F., Bennett, C. L., Barry, M. J., Eden, K. B., Holmes-Rovner, M., Llewellyn-Thomas, H., Lyddiatt, A., Thomson, R., Trevena, L., & Wu, J. H. C. (2014). Decision aids for people facing health treatment or screening decisions. *The Cochrane Database of Systematic Reviews*, (1), Article CD001431. https://doi.org/10.1002/14651858.CD001431.pub4

Steginga, S. K., & Occhipinti, S. (2006). Dispositional optimism as a predictor of men's decision-related distress after localized prostate cancer. *Health Psychology*, *25*(2), 135–143. https://doi.org/10.1037/0278-6133.25.2.135

Strathman, A., Gleicher, F., Boninger, D. S., & Edwards, C. S. (1994). The consideration of future consequences: Weighing immediate and distant outcomes of behavior. *Journal of Personality and Social Psychology*, *66*(4), 742–752. https://doi.org/10.1037/0022-3514.66.4.742

Sung, L., Klaassen, R. J., Dix, D., Pritchard, S., Yanofsky, R., Ethier, M. C., & Klassen, A. (2009). Parental optimism in poor prognosis pediatric cancers. *Psycho-Oncology*, *18*(7), 783–788. https://doi.org/10.1002/pon.1490

Thyen, U., Kuhlthau, K., & Perrin, J. M. (1999). Employment, child care, and mental health of mothers caring for children assisted by technology. *Pediatrics*, *103*(6), 1235–1242. https://doi.org/10.1542/peds.103.6.1235

Tomlinson, D., Bartels, U., Gammon, J., Hinds, P. S., Volpe, J., Bouffet, E., Regier, D. A., Baruchel, S., Greenberg, M., Barrera, M., Llewellyn-Thomas, H., & Sung, L. (2011). Chemotherapy versus supportive care alone in pediatric palliative care for cancer: Comparing the preferences of parents and health care professionals. *CMAJ*, *183*(17), E1252–E1258. https://doi.org/10.1503/cmaj.110392

Ubel, P. A., Jepson, C., & Baron, J. (2001). The inclusion of patient testimonials in decision aids: Effects on treatment choices. *Medical Decision Making*, *21*(1), 60–68. https://doi.org/10.1177/0272989X0102100108

Volandes, A. E., Barry, M. J., Chang, Y., & Paasche-Orlow, M. K. (2010). Improving decision making at the end of life with video images. *Medical Decision Making*, *30*(1), 29–34. https://doi.org/10.1177/0272989X09341587

Volandes, A. E., Paasche-Orlow, M. K., Barry, M. J., Gillick, M. R., Minaker, K. L., Chang, Y., Cook, E. F., Abbo, E. D., El-Jawahri, A., & Mitchell, S. L. (2009). Video decision support tool for advance care planning in dementia: Randomised controlled trial. *BMJ*, *338*, Article b2159. https://doi.org/10.1136/bmj.b2159

Watters, K. F. (2017). Tracheostomy in Infants and Children. *Respiratory Care*, *62*(6), 799–825. https://doi.org/10.4187/respcare.05366

Wilfond, B. S. (2014). Tracheostomies and assisted ventilation in children with profound disabilities: Navigating family and professional values. *Pediatrics*, *133*(Suppl. 1), S44–S49. https://doi.org/10.1542/peds.2013-3608H

Wilson, T. D., & Gilbert, D. T. (2003). Affective forecasting. In M. P. Zanna (Ed.), *Advances in experimental social psychology* (Vol. 35, pp. 345–411). Academic Press. https://doi.org/10.1016/S0065-2601(03)01006-2

Wilson, T. D., & Gilbert, D. T. (2005). Affective forecasting: Knowing what to want. *Current Directions in Psychological Science*, *14*(3), 131–134. https://doi.org/10.1111/j.0963-7214.2005.00355.x

Winter, L. (2013). Patient values and preferences for end-of-life treatments: Are values better predictors than a living will? *Journal of Palliative Medicine*, *16*(4), 362–368. https://doi.org/10.1089/jpm.2012.0303

Winterbottom, A., Bekker, H. L., Conner, M., & Mooney, A. (2008). Does narrative information bias individual’s decision making? A systematic review. *Social Science & Medicine*, *67*(12), 2079–2088. https://doi.org/10.1016/j.socscimed.2008.09.037

Winterbottom, A. E., Bekker, H. L., Conner, M., & Mooney, A. F. (2012). Patient stories about their dialysis experience biases others’ choices regardless of doctor’s advice: An experimental study. *Nephrology Dialysis Transplantation*, *27*(1), 325–331. https://doi.org/10.1093/ndt/gfr266

Wise, M., Han, J. Y., Shaw, B., McTavish, F., & Gustafson, D. H. (2008). Effects of using online narrative and didactic information on healthcare participation for breast cancer patients. *Patient Education and Counseling*, *70*(3), 348–356. https://doi.org/10.1016/j.pec.2007.11.009

Zeelenberg, M., Van den Bos, K., Van Dijk, E., & Pieters, R. (2002). The inaction effect in the psychology of regret. *Journal of Personality and Social Psychology*, *82*(3), 314–327. https://doi.org/10.1037//0022-3514.82.3.314

Zhao, X., Huang, C., Li, X., Zhao, X., & Peng, J. (2015). Dispositional optimism, self-framing and medical decision-making. *International Journal of Psychology*, *50*(2), 121–127. https://doi.org/10.1002/ijop.12079

Chapter 3 Development of Education Materials Describing the Experiences Associated with Pediatric Tracheostomy Using User-Centered Design

Introduction

With advances in medicine, tracheostomies are increasingly being placed in critically ill pediatric patients to enable long-term breathing support (Namachivayam et al., 2010; Yaneza et al., 2015). Nevertheless, clinicians and parents often debated the burden versus benefits of tracheostomies, because while a tracheostomy may shorten hospital stay and improve the patient’s comfort, it comes with big commitment of the caregiver and uncertainty in patient prognosis, and may extend a low quality of life (Hebert et al., 2017; McPherson et al., 2017; Wilfond, 2014).

Making a tracheostomy placement decision for a critically ill child is challenging for parents in various ways. Many tracheostomy decisions imply serious and irreversible outcomes, entailing a choice among options such as accepting a life-support-dependent future for the child, prioritizing the child’s comfort and allowing death, and indefinite hospitalization (Nageswaran et al., 2018). No option is likely to be seen as clearly positive and each has significant long-term implications for the child and the family. Thus, during decision making, parents have to deliberate many goals and interests such as the child’s quality of life, the norm of being a “good parent,” and the desire to “never give up” (Feudtner et al., 2015; Roscigno et al., 2012).

As a result, parents often have many questions and worries about their child and their family. From Chapter 1, we know that parents have difficulty judging how long their children would need a tracheostomy and how much they would suffer from this invasive surgery. Parents also worry about their ability to handle home care and changes to their family's daily routines. There may not be a simple answer to these questions due to the nature of uncertainty and individualized situations. As a result, while parents have expressed a desire of information and experience-sharing, they may not always have the knowledge and understanding that they need to make the most informed and effective decisions possible.

Forecasting Errors

One of the most problematic challenges that parents face when making tracheostomy decisions is that they may fall prey to forecasting errors when evaluating alternatives and preparing for possible outcomes. There are two main ways that forecasting the future can go wrong: 1) inaccurate judgments of the likelihood, duration, or intensity of possible outcomes (Gilovich et al., 2002; Wilson & Gilbert, 2003, 2005); and 2) misconstrual of what the future may entail (as discussed in Gilbert et al., 1998). For instance, some parents expect shorter duration of tracheostomy than what actually happened (Demke et al., 2008). Parents may mistakenly think that offering the tracheostomy option implies hope for recovery (Nelson et al., 2005). These inaccurate judgments could be the result of biased judgment process, such as focusing on salient differences between options and ignoring other relevant aspects (Schkade & Kahneman, 1998), reasoning in favor of one's hopes (Kruger & Burrus, 2004; Kunda, 1990), or lacking relevant information.

Forecasting errors are not only common, but also consequential in many health decisions. For example, when men receive the news that they have prostate cancer, they tend to overestimate their fear and anxiety over time (Loewenstein, 2005) or focus on treatments' perceived ability to control prostate cancer (Zeliadt et al., 2006). As a result, they are likely to choose the intrusive treatment, which is sometimes a suboptimal choice that conflicts with their values (Loewenstein, 2005; Zeliadt et al., 2006). People may misjudge quality of life regarding different treatments and underestimate their ability to adapt to illnesses, resulting in rejection of certain beneficial treatments (Riis et al., 2005). Cancer patients overestimate their probabilities of survival and thus choose life-extending therapy and aggressive treatments that induce suffering without increasing survival (Weeks et al., 1998). All these forecasting errors are associated with final decisions that may not fully align with a person's long-term interests. Researchers have recognized the need to study forecasting errors and develop decision support for more informed decision making (Halpern & Arnold, 2008).

Pediatric tracheostomy decisions may be subject to forecasting errors due to a lack of experience and expertise. First, it is likely that parents have no experience making this decision. From the interview study in Chapter 1, many parents reported that they were overwhelmed by these decisions because they never had to go through this previously. Moreover, many of them had never experienced or imagined the impact of these decisions. They may later realize that there is more to do when the child grows older (Carnevale et al., 2006). Many parents are not medical professionals and rely on providers and online resources for information. However, physicians tend not to discuss short- and long-term implications and challenges in shared decision making (Hebert et al., 2017; Nelson et al., 2007), and parents may not feel adequately informed about and prepared for life after the tracheostomy placement (McCormick et al., 2015).

Narratives as Information Support

Parents appear at least somewhat aware of their knowledge deficits and consider becoming better informed essential to facilitate decision making (October et al., 2014). In particular, realizing that clinicians may not be the sole source of information, many parents perceive that learning the perspectives of other parents who have been in the same situation will be valuable. Parents report wanting to learn about how other parents take care of their children at home and outside. Parents also want emotional support (e.g., encouragement or empathy) from peer parents. However, they often do not have an opportunity to meet or talk with another family (Carnevale et al., 2006; McCormick et al., 2015). All these unmet information and emotional needs may ultimately result in dissatisfaction with the decision process and outcomes (October et al., 2020).

To address forecasting errors and fulfill parents' need for information from peer parents, we sought to create education materials about important possible outcomes associated with tracheostomy that would share the experiences of those parents who have already "been there." The primary purpose was to *inform* parents about important considerations (challenges in particular) of quality of life and typical life experiences with a child on tracheostomy. The secondary purpose was to *comfort* parents by normalizing emotional and practical challenges during and after tracheostomy decision making. To achieve these two purposes, we aimed to integrate the experiences of many different parents who had previously faced tracheostomy decisions into a set of carefully targeted short narratives on critical topics. Our design goal was not to present word-for-word stories shared by parents but rather to create representative narratives that specifically address different forecasting errors based on real experiences from direct discussions with parents who have made these decisions. According to the Narrative Immersion Model (Shaffer et al., 2018), a constructed narrative can be as effective as a real story as long as it appears realistic, credible, and engaging. Therefore, the education materials were organized by topical domain (which aligned with the type forecasting errors possible) and used narratives as concrete illustrations of the types of experiences associated with tracheostomy in order to increase parents' understanding of these details.

User-Centered Design

We used a user-centered design (UCD) process to iteratively collect parents' feedback and repeatedly revise the design and content of the education materials to maximize their value to future parents. It refers to an iterative design and evaluation process in which the product development is guided by end-users' feedback (e.g., users' goals, needs, and interactions with the prototype) so that the final product will be effective for intended users (Karat, 1997; Ritter et al., 2014; Schneidermeier et al., 2013). The intellectual concept of UCD stemmed from fields such as human factors, ergonomics, and engineering. The term UCD was first coined by Norman and Draper in 1986 (Ritter et al., 2014). Over time, researchers have summarized key principles of UCD. According to ISO 9241-210 (2010), as cited in Schneidermeier et al. (2013), it embodies six principles: "1) The design is based upon an explicit understanding of users, tasks and environments; 2) Users are involved throughout design and development; 3) The design is driven and refined by user-centered evaluation; 4) The process is iterative; 5) The design addresses the whole user experience; 6) The design team includes multidisciplinary skills and perspectives." These principles ensure that users are involved throughout the process and the design is driven by their feedback with experts' input.

User-centered design has been applied in many domains, for instance, website (Corry et al., 1997) and software development (Kangas & Kinnunen, 2005), new product development (Veryzer & Mozota, 2005), and education (McKnight et al., 1996). A survey of experienced UCD practitioners showed that a majority observed significant improvements in usefulness and usability of products due to applications of UCD (Mao et al., 2005).

Although the use of UCD is recommended for enhancing user experience, there are only limited applications of UCD in healthcare (Gurses et al., 2012; Searl et al., 2010). According to Zhang (2005), the healthcare system has not had a culture of fitting health technology to people's characteristics. This lack of application could be due to reasons such as under-appreciation of usability testing and users' needs, limited time and expertise for product development (Mayhew & Mantei, 1994). Nevertheless, recently there is a growing body of applications of UCD in the health domain. For example, a literature review on the effects of UCD methods on diabetes-related consumer health informatics technology concluded that researchers reported improved usability, usage, understanding of users' requirements, etc (LeRouge & Wickramasinghe, 2013). Asking user-centered design groups (patients and caregivers) for feedback led to an improved health information technology tool for pediatric hematopoietic cell transplantation patients (Maher et al., 2016). Taylor et al. (2003) employed UCD to develop a highly usable web-based amblyopia screening for preschool children.

We used UCD to develop our education materials in order to keep the focus on meeting parents' needs for information and emotional support. Based on the research findings, current information support may focus heavily on what the providers want parents to know and often does not answer some questions that parents consider important for making an informed decision. Obtaining parents' qualitative feedback via direct contact with the materials and interviewers' probing questions provides richer information for us to understand parents' goals and context of use than other methods such as surveying parents and simply receiving comments from them. The iterative design process allows us to constantly evaluate the usability of the materials.

General Method

We engaged parents who have gone through tracheostomy decision making to provide feedback for creating the education materials designed to fill in the information gap of understanding tracheostomy. The study was declared exempt research by the University of Michigan Medical School Institutional Review Board (IRBMED).

Eligibility

Parents were eligible for the study if they 1) were fluent in English and were at least 18 years of age at the time of enrollment, 2) had made a tracheostomy decision for their child, with or without chronic mechanical ventilation, between about 6 months and 3 years prior to the interview, and 3) considered themselves knowledgeable about the child's condition and services, both at the time of the tracheostomy decision and afterwards. In addition, the child whose tracheostomy decision had been made should have met the following criteria: 1) The child was less than 18 years of age at the time of decision making; 2) the child had a life-limiting illness, in which either a decision to pursue or a decision not to pursue tracheostomy would be ethically appropriate; and 3) the child was a current patient, or had been a patient at the time of tracheostomy decision making at the study site approved by IRBMED. In addition, the current state of the child could be one of the following: 1) If a tracheostomy was pursued: alive, subsequently decannulated, or deceased (more than 6 months ago prior to the interview, in order not to interrupt the bereavement process); 2) if a tracheostomy was declined at that time of decision making: alive, or deceased (more than 6 months ago prior to the interview).

Recruitment

We aimed to recruit about 20 parents. Eligible parents were recruited by one of the following ways: 1) clinicians' recommendation of parents who would potentially meet the above criteria by medical chart review; 2) mass email to a group of parent volunteers sent by a volunteer coordinator at the study site; 3) flyers and brochures distributed on the study site. For potentially eligible and interested parents, their children's relevant medical information and their responses to the screening questions were reviewed before enrollment to ensure their eligibility and suitability for the study.

Data Collection

We conducted 20 user interviews (*n* = 10 for each design phase) between September 2019 and February 2020 at convenient mutually-agreed locations by the parents and interviewer. There were two design phases of the study. We constructed a specific structured interview guide and materials to gather parents' feedback for each phase. All interviews were audio-recorded. Each participant was compensated $50 for the study and travel incentives.

Data Analysis

The audio recordings were transcribed verbatim and checked by two undergraduate research assistants for completeness and accuracy. The analytic process focused on critical feedback insights rather than a broader thematic analysis. After Phase 1 data collection, key data were analyzed to develop the prototype materials. In Phase 2, after completion of each wave, we analyzed and discussed feedback to revise the materials. This process continued until the team was confident about the education materials' purpose, design, and applicability to this population.

Phase 1

The first phase aimed to identify the most important informational needs to be included in the education materials. Specifically, we asked parents to identify which forecasting errors they perceived to be problematic for informed decision making and give feedback on five narratives of issues that they considered the most problematic.

Materials

Forecasting Errors and Narratives

To understand the most problematic issues for informed decision making, we first identified four key domains where forecasting errors might be common and more information support is warranted: considerations of quality of life, home care skills, material constraints, and impact on family life. We developed a list of 15 single-sentence descriptions of forecasting errors in these domains (Appendix D).

To begin with, parents reported valuing quality of life when making medical decisions for their children (Feudtner et al., 2015), but parents may have different expectations of quality of life in the tracheostomy decision context where they encounter focusing illusion and misconstrual. For example, some parents focus on survival rather than other consequences for critically ill children (Carnevale et al., 2011; Michelson et al., 2009; Nageswaran et al., 2018) and anticipate regret and guilt if they believe they have taken away a chance of survival (Sharman et al., 2005). Some may hold overly optimistic hopes about the child's prognosis and the possibility of going home but may not think about what life would look like when the child ends up with a tracheostomy and ventilation in the long term (Carnevale et al., 2006; Demke et al., 2008; Kirk, 2001). Therefore, we constructed five descriptions to illustrate focalism on the near versus distant outcomes.

In addition, parents often assume a natural duty of taking care of their child without understanding the reality of home care (Kirk, 2001). Research has shown that parents are not fully prepared for transitioning the care to home, handling emergencies and complications, and coordinating healthcare visits (Hopkins et al., 2009; McCormick et al., 2015). Therefore, some parents may underestimate the burden of long-term commitment. Accordingly, we constructed three items for the home care skills category.

Professional and social support are important to sustain the care for a child with tracheostomy needs. However, care and public resources may not be as easily accessible as parents expect. Getting suitable housing (Edwards, 2004) and support from the community (Carnevale et al., 2006) are challenges parents often encounter during or after the tracheostomy decision. Parents may also overestimate the quantity and quality of home nursing care. It has been reported that parents felt stressed about inadequate nursing coverage to maintain their own well-being (Hefner & Tsai, 2013; Hopkins et al., 2009; Meltzer et al., 2010). We constructed four items to describe these forecasting errors.

Furthermore, caring for a child with tracheostomy has impact on the family's income, relationships, and social life. Some families experience employment and financial struggles (Hefner & Tsai, 2013; Hopkins et al., 2009; Thyen et al., 1999). Broken family relationship (i.e., marriage, parent-child) and social isolation were found associated with caregiving responsibilities of a child with a tracheostomy (Carnevale et al., 2006; Edwards, 2004; Flynn et al., 2013; Montagnino & Mauricio, 2004). We created three items to describe these types of issues.

For each of the 15 forecasting errors, we constructed a short narrative based on the above mentioned literature, the interview data from Chapter 1, and conversations with clinicians experienced in tracheostomy decisions. Experts including decision scientists (H.Y., B.Z.), a pediatrician in palliative care (K.P.), and a neonatologist (S.K.) reviewed the narratives to ensure that they captured the core idea of the corresponding forecasting errors and presented accurate medical knowledge and realistic patient experiences without medical jargon.

Interview Guide

The interview guide was designed and piloted with undergraduate research assistants multiple times to make sure that it would be easy for participants to understand what the questions were asking for. It included four steps. The first step aimed at preparing parents for talking about their tracheostomy decision making for the study. It contained questions that asked about any difficulties during the decision process and their information needs. The tracheostomy decision process can be stressful and overwhelming to talk about and therefore we designed these questions to not only understand the decision-making environment (the context in which the materials will be used), but also guide parents to think about their challenges when making the decision.

The second step was a card sorting task in which parents were asked to sort the 15 forecasting errors into three categories—very problematic, somewhat problematic, or not problematic—for informed decision making if they occurred. We also asked for rationale of the sorting individually and as a group and whether these errors were realistic. While all of these forecasting errors are possibly relevant to tracheostomy decisions, our goal was to identify which errors were seen by parents as most critical to address. This step sought to understand the tasks and experiences of the participant parent and other parents and involve them in the development of future prototype materials.

In the third step, we showed parents narratives that corresponded to the forecasting errors they perceived to be the most problematic and asked them whether they thought the narratives conveyed the core issues. We also elicited actionable feedback about what they would keep or change in the narratives. This step was designed to include parents in developing narratives for the prototype materials.

In the fourth step, we sought to understand when parents desired information about how tracheostomy influences daily life and in what form the educational materials should be. This would help us set the tone and format of the prototype materials. This step corresponded to the UCD principles of understanding the task environment and whole user experience.

Procedure

We first explained the study and asked parents to sign the consent form. We started the session by asking parents to reflect on their information needs at the time of decision making and surprises about decision outcomes. Then, we presented participants with descriptions of forecasting errors, asked them to identify what they perceive as more versus less problematic for parents to make an informed decision, and requested feedback on the five draft narratives of the forecasting errors they viewed as the most problematic. Lastly, we elicited feedback about how and when such information should be delivered. Parents then filled out a demographics and experiences survey.

Results

Ten parents were interviewed for Phase 1. Parent and child demographics and information are reported in Tables 3.1 and 3.2.

Table 3.1 Participants' Demographics (N = 20)

Demographics	Phase 1 (*n* = 10)	Phase 2 (*n* = 10)*
Relation to patient, n (%)		
Biological mother	8 (80)	8 (80)
Biological father	1 (10)	1 (10)
Legal guardian/Adoptive mother	1 (10)	1 (10)
Age, median (range)	37 (28–64)	41.5 (28–45)
Race, n (%)		
White	10 (100)	8 (80)
Mixed (Black or African American with one other race)	0 (0)	2 (20)
Hispanic, n (%)	0 (0)	1 (10)
Marital status, n (%)		
Single	1 (10)	1 (10)
Married	8 (80)	7 (70)
Single/Partnership	1 (10)	0 (0)
Divorced	0 (0)	1 (10)
Separated	0 (0)	1 (10)
Education, n (%)		
High school	1 (10)	0 (0)
Some college or post-high school education	1 (10)	5 (50)
College graduate	5 (50)	4 (40)
Master's degree or higher	3 (30)	1 (10)
Household income, n (%)		
<$30,000	2 (20)	1 (10)
$30,000-$59,999	2 (20)	3 (30)
$60,000-$89,999	2 (20)	1 (10)
>$90,000	4 (40)	4 (40)
Rather not say	0 (0)	1 (10)

*One parent also participated in Phase 1.

Table 3.2 Parent-Reported Children's Information (N = 20)

Characteristics*	Phase 1 (*n* = 10)	Phase 2 (*n* = 10)†
Age (range)‡	3 months – 15 years 4 months	3.5 months – 10 years
Age at tracheostomy decision (range)	1 month – 14 years 6 months	At birth – about 10 years
Duration of tracheostomy if applicable (range)‡	3 months – 1 year ongoing	1 year and 9 months – 3 years ongoing
Sex, n (%)		
Boys	7 (70)	4 (40)
Girls	3 (30)	6 (60)
Race, n (%)		
White	9 (90)	6 (60)
Black	1 (10)	0 (0)
Mixed (White with one other race)	0 (0)	3 (30)
Hispanic	0 (0)	1 (10)
Final decision, n (%)		
Tracheostomy with ventilator	4 (40)	5 (50)
Tracheostomy without ventilator	2 (20)	0 (0)
No tracheostomy	4 (40)	5 (50)
Current condition, n (%)		
Tracheostomy with ventilator, alive	3 (30)	4 (40)
Tracheostomy without ventilator, alive	2 (20)	0 (0)
Tracheostomy removed, alive	0 (0)	1 (10)
No tracheostomy, alive	3 (30)	1 (10)
Deceased more than 6 months ago	2 (20)	4 (40)

* Parents reported that their children had diverse diagnoses, including chromosomal disorders (e.g., trisomy 18), musculoskeletal syndromes, rare genetic conditions, brain malformations and injury (e.g., cerebral palsy), pulmonary pathology (e.g., bronchopulmonary dysplasia and malacia).

† One child was also included in Phase 1.

‡ birth to date of interview or date of death

Overall parents reflected that all 15 forecasting errors were realistic issues that might be problematic for making an informed tracheostomy decision. Based on their feedback on forecasting errors and selective narratives, we identified several key components that should be reflected in the content and tone of the prototype materials.

Child's Quality of Life as Core Value

Parents acknowledged that they should consider factors other than survival but emphasized that the decision should be made based on the child's best interest rather than convenience and needs of the parent caregivers. However, parents reported diverse expectations and perceptions of best interests. Some parents adjusted their expectations of what their children could do with medically complex conditions and valued tracheostomy as a means for the child to thrive—gaining weight and meeting development milestones, although their child's life expectancy was likely to be shorter than that of most people. Other parents considered tracheostomy as a threat to the child's comfort and current active life. Either way, parents wished to know more about the future outcomes, both pros and cons of tracheostomy, at the time of decision making.

These responses suggested that the quality-of-life outcomes of tracheostomy could be highly individualized. The outcomes were not all negative or positive. Therefore, it would be important to present different perspectives in the prototype materials.

Details about Home Care

Caring for a child with a tracheostomy at home entails many skills and coordination between family members and home care nurses. Parents considered insufficient preparation regarding home care very problematic. Parents reported that the caregivers ought to be prepared to take on routine tasks, such as suctioning, changing the tracheostomy tube and its ties, and respond to emergencies. Otherwise, the caregivers would be stressed and the child’s life may be at great risk due to inadequate care. In addition, parents reported that insufficient availability of competent and reliable nurses was one thing that parents talked a lot about in support groups. Therefore, parents should be aware of nursing shortage and be prepared to take the responsibility of teaching and guiding home care nurses in the care needs of their individual children.

These responses suggested that the prototype materials should include what home care looks like and ways to manage home care.

Diversity of Situations and Outcomes

One theme throughout the participants’ responses was that every patient and family could have unique situations so that some forecasting errors might be more consequential for some patients’ families than for others. For instance, some resourceful families might have done ample research and training on tracheostomy care and thus have found the care less scary than expected. Regarding reduction in household income, having a child with a tracheostomy might significantly impact household income if both parents used to work but might have little or no influence if one parent already stayed at home. Family relationship and social life could also depend on how strong the family’s circle is—having a child with a tracheostomy may bring positive or negative impact. In terms of practical support such as housing and facilities, it could depend on the location of the household and resources provided in that community.

These responses suggested that it would be important to ensure readers understand that the reality might be better or worse than expected, although our focus was to present challenges to help parents prepare for negative outcomes.

Emotional Support and Advice

Parents described that both making the decision and taking care of a child with tracheostomy could be scary and emotional. They said it would be important to get emotional support and know that other parents have similar feelings. They would not only want to know the challenges, but also support and solutions for those issues to preserve some positivity in life.

These responses suggested that while at first it would be helpful to share the stress and challenges faced by many families, it would be equally important to offer parents support and build their confidence in dealing with these emotional and practical challenges.

In addition, parents gave us feedback about when and how the information should be delivered to them.

Timely Information

Most parents preferred to get information about the tracheostomy placement procedure and influences on everyday life as soon as it became an option. Parents appreciated ample time to digest the information and get prepared before doctors officially brought up the need to make a decision. Having information prior to the family meeting would help them ask the right questions. Having information after the consultation would enable parents to ponder over their most relevant issues. Therefore, the prototype we designed focused providing a variety of perspectives and matters for parents to consider without the pressure to decide.

Multiple Ways to Deliver the Information

Parents preferred multiple ways to deliver the information, such as a short video, pamphlets, website, and app, although each way has its upsides and downsides. They also noted that some parents may not be literate so an audio version might be helpful. We decided to make a short booklet because it is a simple and efficient way to present information and it could be adapted to other formats (e.g., website, video) relatively easily.

Discussion

These findings implied several important issues for developing the prototype. First, parents wanted to make the decision for the child's best interest not theirs, which is consistent with one of the good-parent belief of "putting the child's needs above my own" (Feudtner et al., 2015). This illustrates parents' goal of obtaining relevant information is to make the best decision for the child, so we should first focus on possible outcomes of the child. While the caregivers' physical and mental health is important, the education materials should reflect a delicate balance of describing different types of challenges and not frame the situation as a tradeoff between the interests of the child and caregivers. Second, since parents worried most about not knowing specific details of tracheostomy home care, we decided to provide more detailed narratives on this topic to fulfill the identified needs. Third, there appeared to exist an issue of balance of positive and negative aspects in these materials. For example, parents mentioned that these forecasting errors may have different impact on different families, so we decided to acknowledge and describe different levels of impact explicitly in the narratives. Moreover, the narratives of the forecasting errors focused on negative aspects of the lived experiences. While the negative tone validated parents' feelings, it could be overwhelming to learn about all the challenges without ways to deal with them. Therefore, in the education materials, we decided to present not only the challenges but also useful advice shared by parents. Fourth, we learned that parents wanted information as early as possible, so it would be important to set an open-minded tone for the education materials and to focus on getting parents think about these issues. These takeaways addressed users' whole experience by attending to their urgent needs for diverse perspectives and solutions.

Phase 2

The second phase (4 waves of 2–4 individual user interviews each) focused on eliciting feedback on the education materials prototype. The first three waves each included two parents and the final wave included four.

Materials

Booklet

We developed a prototype booklet of narratives based on parent participants' feedback obtained in Phase 1. The draft was an integration of parents' feedback and design team's expertise and perspectives. The booklet contained a general introduction of the tracheostomy decision, parents' experiences of quality of life, home care responsibilities, practical support, and a resources page (Table 3.3). To make it easy for parents to understand and follow, each section was organized by key takeaway points with narratives in simple vocabulary and large prints. The initial concept was that parents could read the booklet before a meeting and take home as appropriate. The goal of Phase 2 was to revise the booklet iteratively based on parents' and professionals' feedback.

Table 3.3 Sections of the Booklet

Section Title	Major Content
Introduction	Introduction of the aims and content of the booklet
What is my child's best interest?	Diverse perspectives of long-term quality of life
What should I expect with a tracheostomy?	Home care skills and home nursing
What else should I know?	Home environment, financial impact, support from schools and public, changes in family dynamics
What if I have more questions?	Support group resources

Interview Guide

Step 1 was the same as that in Phase 1. Step 2 aimed to obtain parents' perceptions of important, concerning, and unnecessary parts of the booklet so that we would know what to keep, change, or add. These questions were designed to acquire an explicit evaluation and understanding of whether the booklet adequately conveyed parents' experiences and held value for helping future parents understand these topics. In the second and third wave, we focused more on probing less important points that could be taken out and the third wave added one question about whether to take out or combine stories in the "support from schools and public" section. Step 3 was similar to Step 4 in Phase 1.

Procedure

Similar to Phase 1, after obtaining participants' informed consent, we started the session by asking parents about their tracheostomy decision-making experiences. (This step was omitted for the parent who had participated in Phase 1.) Then, we presented participants with the prototype education materials and asked for feedback on the content and length. In the last part of the interview, we asked parents when the booklet should be delivered and whether the booklet would be a good way to present such information. At the conclusion of the session, parents completed a survey about their demographics and tracheostomy-related experiences.

Results

Parent and child demographics and information for Phase 2 are reported in Tables 3.1 and 3.2.

The booklet was updated four times based on parents' and professionals' feedback. Below, we summarize the iterative revision process by wave (See Appendix E for a detailed listing of changes). Overall, parents found the booklet easy to follow and at the right length despite the fact that it was 15 pages long. It was clear that they considered this booklet useful to have as soon as tracheostomy became an option.

Wave 1 (n = 2)

Positive Feedback. Both participant parents found the booklet easy to understand, realistic, and useful. They valued informing parents about the downsides and risks of tracheostomy (impact on child and home care responsibilities) because the challenges of tracheostomy should not be underemphasized and it would be important to be prepared for life changes. They appreciated diverse perspectives of child's quality of life and the information about the uncertainty of the length of tracheostomy. Both of them found the sections about home care and other practical matters useful, because they addressed realistic challenges and caregivers' own needs, which were often neglected.

Constructive Feedback. Both participant parents expressed the concern that the introduction made tracheostomy sound elective and recommended that a tracheostomy should be presented as essential for survival at the beginning of the booklet. Therefore, we emphasized that tracheostomy provides "a stable airway" and without it "some patients may not live long" in the first paragraph of the introduction. In addition to explaining to parents that the best choice is at the individual family's discretion, one parent recommended reiterating this point after the quality-of-life narratives because parents might doubt themselves after reading perspectives that conflicted with their values. Given all the challenges in finding support, these parents recommended telling parents who would face a tracheostomy decision that this decision would change caregivers' life and that they should be comfortable taking care of the child first before relying on other resources to support the care. Parents provided suggestions to make the narratives more concrete and vivid, such as adding stories about Supplemental Security Income

(SSI), utility bills, and emotional toll of the caregivers, and perspectives of a single parent whose partner left, so we added these details.

Wave 2 (n = 2)

Positive Feedback. Both participant parents found all the content useful. They considered the introduction helpful because it laid out technical pros and cons, main tasks, and important questions that parents should think about during decision making. Both of them acknowledged the importance of diverse perspectives and individual choice. They considered the home care challenges realistic and liked the idea that parents should accept the care responsibilities first.

Constructive Feedback. Regarding the "life-and-death" nature of tracheostomy, one parent still found our previous revision unsatisfactory, as we made "death" without a tracheostomy sound probabilistic. Thus, we articulated the high-stakes consequences ("last resort to optimize the chances for long-term survival") to illustrate importance of this decision. One parent recommended emphasizing the decision could be "life-altering" rather than just "you may not be able to work" as what we added in the previous wave.

One salient issue was the balance of positive and negative narratives. While one parent had more negative perceptions of getting support and suggested adding more details about financial difficulties and family relationship changes, the other parent in this wave perceived these narratives too negative and suggested adding positive stories about home care nurses and family's support. As our booklet focused on describing challenges, we added positive scenarios in the narration and not as an individual story. Both parents, however, provided some advice to deal with these challenges, such as making other children's voice heard in the care plan, starting to go out to get some social life, and consulting with education intervention programs.

One parent suggested that parents should have a team (palliative care in particular to discuss goals of care) with them to go through the booklet rather than read it alone. This was an important suggestion about how this booklet should be used, so we added this message at the end of the section.

Wave 3 (n = 2)

When revising the booklet after this round of feedback, we focused on generalizing key ideas in the narratives. We took out various detailed statements that participant parents had controversies about and details about the specific hospital they attended.

Positive Feedback. Again, the participant parents applauded the descriptions of upsides and downsides of a tracheostomy and parents' thought process. The messages that every child is different and that finding a team to go through the process together were well received. Both parents considered home care and other practical challenges realistic.

Constructive Feedback. Balance of positive and negative aspects was still an issue. In particular, one parent had quite positive experiences. They appreciated different perspectives but disliked the focus on negative outlook of quality of life, because some children with tracheostomies could enjoy many aspects of life. Similar to the previous wave, while parents described more challenges, they suggested adding some advice and illustrating the adaptation for balance. For example, both parents wanted to emphasize that confidence and comfort with care would increase with practice and experience.

Wave 4 (n = 4)

Positive Feedback. The participant parents commented that the booklet was in an excellent shape. In particular, they noted that the narratives were not only vivid as though other parents were talking but also to the point. The narrations summarized key points well. Again, the parents valued different perspectives of quality of life and individual choice.

Constructive Feedback. As for the issue of balance, one parent suggested adding the idea that nurses could be good partners in care and advice such as home schooling and couples counseling. Another parent suggested taking out the concrete details of home care nurses' behaviors and mixing some hope, for instance, "you will have a good social life eventually" and "you will have good support." Although we could not guarantee a good outcome, we illustrated the idea of adaptation in the revision.

Our booklet was designed to give parents information about tracheostomy early in the decision process. One parent shared her experience and pointed that later tracheostomy might not be an option any more. We thought it would be worth presenting the idea that tracheostomy might not always be an option.

Discussion

The UCD process deepened our understanding of parents' needs for messages and information and led to numerous specific changes in the tone and content to better align with parents' experiences. To begin with, these participant parents helped us refine the tone of the booklet. From Phase 1, we learned that families could make different choices depending on their values and judgments of child's conditions and used this tone in the prototype booklet. However, parents in Phase 2 pointed out that this message should be conveyed even more strongly than what our original design did. For instance, parents recommended reiterating this point at the end of the "best interest" section and reflecting more details about different kinds of positive and negative experiences in the narratives. In addition, while we tried to avoid presenting a tradeoff between child's and family caregivers' interests, parents in Phase 2 helped us find a way to state the importance of caregivers' physical and mental health because the patient would suffer if the caregivers were too stressed to manage the care. Furthermore, emphasizing diverse individual situations and presenting the tracheostomy option in a nonforceful way came at the cost of downplaying serious outcomes of this decision: life and death for the child, and life alteration for the caregiver. Parents pointed out this downside and provided a solution that we could emphasize these points in certain narrations.

In addition, by interviewing parents with different experiences and backgrounds, we were able to add more perspectives and details to the booklet, although we later made intentional choices to generalize some details to make the narratives more broadly representative of key ideas. Including a variety of enriched narratives helped with the balance issue. While our goal was to focus on conveying challenges and making parents not feel alone, acknowledging positive outcomes and providing advice in the meantime appeared to be helpful for parents to digest information and feel supported.

In terms of user experience, parents confirmed that the booklet was easy to understand and efficient to use. One new point that emerged in this process was that that although parents wanted a lot of information, it could be overwhelming to read the booklet alone without other support. Therefore, the booklet was designed for parents to use with support from others (e.g., providers). Broadly speaking, parents emphasized the importance of having a support system while noting difficulties in getting material and emotional support.

General Discussion

Information support that help parents deliberate child's potential short- and long- term quality of life and home care realities can be useful for increasing knowledge and correcting forecasting errors while validating parents' stress and worries. Parents acknowledged that the four domains of information would be important for parent decision makers to process and appreciate diverse perspectives. Parents also provided valuable feedback on the tone of the booklet and content of the narratives.

The UCD process enabled us to gain a direct understanding of how parents perceived forecasting errors in tracheostomy decision making and how they viewed the tone and content of the booklet. The design was driven by parents and also evaluated by the team. We incorporated constructive feedback based on our understanding of the literature and other parents' experiences in multiple rounds of revision. As we theorized that many forecasting errors were due to incomplete understanding of the challenges, most narratives described negative consequences. Parents offered more specific examples of their perceptions of limited life experiences and their difficulties with emergencies, home care nurses, the community, and other family members. These examples increased concreteness of the narratives and therefore may help parents facing these decisions envision everyday life with a child with a tracheostomy.

On the other hand, it was useful to obtain parents' feedback about emphasizing the uniqueness of each case, adaptation and acceptance, and strategies to deal with some of the challenges (e.g., finding a supportive professional and parental network, interviewing home care nurses), which are all reasonable given existing literature. For instance, research shows diverse outcomes (e.g., discharge, death, decannulation, completion of developmental milestones) in tracheostomy and ventilator-dependent children (Edwards et al., 2010; Funamura et al., 2014; McPherson et al., 2017; Rane et al., 2013). While a systematic review shows that not all parents have increased confidence and acceptance of the child's underlying condition and caring needs over time (Flynn et al., 2013), parents would become experts of their own children (Kirk & Glendinning, 2002; McNamara et al., 2009). However, well-being is often poor in parental caregivers of children with tracheostomies (Gong et al., 2019; Hartnick et al., 2003; Hopkins et al., 2009) and it is unrealistic that parents care for the child without any help.

Caring for a child with complex healthcare needs requires coordination between parents, professionals, and other support networks. Thus, an important part of the booklet presented these challenges and some strategies in order to make parents not feel alone in the process. We emphasized that it would be crucial to maintain caregivers' well-being and establish trusting relationships with other professional parties, such as home care nurses, and medical supply companies (Flynn et al., 2013). Seeking emotional support, practical help, and information from professionals may share parents' care burden and increase confidence (Kirk & Glendinning, 2002).

This study had two limitations that may limit its generalizability. Although we observed some diversity in the participant sample, the participant parents were recruited from a single study site and thus they might share some similar experiences. Nevertheless, these parents enriched our understanding of their experiences and needs and substantially improved the prototype education materials. Future studies can collect feedback from parents from diverse study sites. In addition, this study focused on more devastating cases of tracheostomy decisions where either pursuing tracheostomy or not would be ethically appropriate. More research needs to be done to understand the information needs of parents with other types of tracheostomy decisions.

Our user-centered process yielded a parent-tested tracheostomy information booklet that is ready for implementation in clinical settings. The final version is available for free download (https://deepblue.lib.umich.edu/handle/2027.42/154713). Further work is nonetheless needed to evaluate the impact of using the booklet on improving informed decision making and decision satisfaction in clinical settings. As the first step, we are seeking to incorporate the booklet into goals-of-care consultations for critically ill children at the study site. We will first ask clinicians who are doing these consultations to review the booklet and to discuss feasible ways to use it. As the booklet was designed to be presented to parents as early in the decision process as possible, clinicians may consider asking parents whether they would be willing to receive such information prior to family conferences to get prepared for the consultation. Clinicians may also discuss key points in the booklet during the consultation or provide it to parents after the consultation as an additional source of information. We encourage both providers and parents who are facing discussions of such difficult tracheostomy decision to use this booklet when appropriate. We also appreciate feedback from providers and parents who have used it.

References

Carnevale, F. A., Alexander, E., Davis, M., Rennick, J., & Troini, R. (2006). Daily living with distress and enrichment: The moral experience of families with ventilator-assisted children at home. *Pediatrics*, *117*(1), e48–e60. https://doi.org/10.1542/peds.2005-0789

Carnevale, F. A., Benedetti, M., Bonaldi, A., Bravi, E., Trabucco, G., & Biban, P. (2011). Understanding the private worlds of physicians, nurses, and parents: A study of life-sustaining treatment decisions in Italian paediatric critical care. *Journal of Child Health Care*, *15*(4), 334–349. https://doi.org/10.1177/1367493511420183

Corry, M. D., Frick, T. W., & Hansen, L. (1997). User-centered design and usability testing of a web site: An illustrative case study. *Educational Technology Research and Development*, *45*(4), 65–76. https://doi.org/10.1007/BF02299683

Demke, J., Bassim, M., Patel, M. R., Dean, S., Rahbar, R., van Aalst, J. A., & Drake, A. (2008). Parental perceptions and morbidity: Tracheostomy and Pierre Robin sequence. *International Journal of Pediatric Otorhinolaryngology*, *72*(10), 1509–1516. https://doi.org/10.1016/j.ijporl.2008.07.002

Edwards, E. A. (2004). Sending children home on tracheostomy dependent ventilation: Pitfalls and outcomes. *Archives of Disease in Childhood*, *89*(3), 251–255. https://doi.org/10.1136/adc.2003.028316

Edwards, J. D., Kun, S. S., & Keens, T. G. (2010). Outcomes and causes of death in children on home mechanical ventilation via tracheostomy: An Institutional and literature review. *The Journal of Pediatrics*, *157*(6), 955–959.e2. https://doi.org/10.1016/j.jpeds.2010.06.012

Feudtner, C., Walter, J. K., Faerber, J. A., Hill, D. L., Carroll, K. W., Mollen, C. J., Miller, V. A., Morrison, W. E., Munson, D., Kang, T. I., & Hinds, P. S. (2015). Good-parent beliefs of parents of seriously ill children. *JAMA Pediatrics*, *169*(1), 39–47. https://doi.org/10.1001/jamapediatrics.2014.2341

Flynn, A. P., Carter, B., Bray, L., & Donne, A. J. (2013). Parents' experiences and views of caring for a child with a tracheostomy: A literature review. *International Journal of Pediatric Otorhinolaryngology*, *77*(10), 1630–1634. https://doi.org/10.1016/j.ijporl.2013.07.020

Funamura, J. L., Durbin-Johnson, B., Tollefson, T. T., Harrison, J., & Senders, C. W. (2014). Pediatric tracheotomy: Indications and decannulation outcomes. *The Laryngoscope*, *124*(8), 1952–1958. https://doi.org/10.1002/lary.24596

Gilbert, D. T., Pinel, E. C., Wilson, T. D., Wheatley, T. P., & Blumberg, S. J. (1998). Immune neglect: A source of durability bias in affective forecasting. *Journal of Personality and Social Psychology*, *75*(3), 617–638. https://doi.org/10.1037/0022-3514.75.3.617

Gilovich, T., Griffin, D., & Kahneman, D. (Eds.). (2002). *Heuristics and biases: The psychology of intuitive judgment*. Cambridge University Press. https://doi.org/10.1017/CBO9780511808098

Gong, S., Wang, X., Wang, Y., Qu, Y., Tang, C., Yu, Q., & Jiang, L. (2019). A descriptive qualitative study of home care experiences in parents of children with tracheostomies. *Journal of Pediatric Nursing*, *45*, 7–12. https://doi.org/10.1016/j.pedn.2018.12.005

Gurses, A. P., Ozok, A. A., & Pronovost, P. J. (2012). Time to accelerate integration of human factors and ergonomics in patient safety. *BMJ Quality & Safety*, *21*(4), 347–351. https://doi.org/10.1136/bmjqs-2011-000421

Halpern, J., & Arnold, R. M. (2008). Affective forecasting: An unrecognized challenge in making serious health decisions. *Journal of General Internal Medicine*, *23*(10), 1708–1712. https://doi.org/10.1007/s11606-008-0719-5

Hartnick, C. J., Bissell, C., & Parsons, S. K. (2003). The Impact of pediatric tracheotomy on parental caregiver burden and health status. *Archives of Otolaryngology–Head & Neck Surgery*, *129*(10), 1065–1069. https://doi.org/10.1001/archotol.129.10.1065

Hebert, L. M., Watson, A. C., Madrigal, V., & October, T. W. (2017). Discussing benefits and risks of tracheostomy: What physicians actually say. *Pediatric Critical Care Medicine*, *18*(12), e592–e597. https://doi.org/10.1097/PCC.0000000000001341

Hefner, J. L., & Tsai, W. C. (2013). Ventilator-dependent children and the health services system. Unmet needs and coordination of care. *Annals of the American Thoracic Society*, *10*(5), 482–489. https://doi.org/10.1513/AnnalsATS.201302-036OC

Hopkins, C., Whetstone, S., Foster, T., Blaney, S., & Morrison, G. (2009). The impact of paediatric tracheostomy on both patient and parent. *International Journal of Pediatric Otorhinolaryngology*, *73*(1), 15–20. https://doi.org/10.1016/j.ijporl.2008.09.010

Kangas, E., & Kinnunen, T. (2005). Applying user-centered design to mobile application development. *Communications of the ACM*, *48*(7), 55–59. https://doi.org/10.1145/1070838.1070866

Karat, J. (1997). Evolving the scope of user-centered design. *Communications of the ACM*, *40*(7), 33–38. https://doi.org/10.1145/256175.256181

Kirk, S. (2001). Negotiating lay and professional roles in the care of children with complex health care needs. *Journal of Advanced Nursing*, *34*(5), 593–602. https://doi.org/10.1046/j.1365-2648.2001.01788.x

Kirk, S., & Glendinning, C. (2002). Supporting ‘expert’ parents—professional support and families caring for a child with complex health care needs in the community. *International Journal of Nursing Studies*, *39*(6), 625–635. https://doi.org/10.1016/S0020-7489(01)00069-4

Kruger, J., & Burrus, J. (2004). Egocentrism and focalism in unrealistic optimism (and pessimism). *Journal of Experimental Social Psychology*, *40*(3), 332–340. https://doi.org/10.1016/j.jesp.2003.06.002

Kunda, Z. (1990). The case for motivated reasoning. *Psychological Bulletin*, *108*(3), 480–498. https://doi.org/10.1037/0033-2909.108.3.480

LeRouge, C., & Wickramasinghe, N. (2013). A review of user-centered design for diabetes-related consumer health informatics technologies. *Journal of Diabetes Science and Technology*, *7*(4), 1039–1056. https://doi.org/10.1177/193229681300700429

Loewenstein, G. (2005). Hot-cold empathy gaps and medical decision making. *Health Psychology*, *24*(Suppl. 4), S49–S56. https://doi.org/10.1037/0278-6133.24.4.S49

Maher, M., Kaziunas, E., Ackerman, M., Derry, H., Forringer, R., Miller, K., O’Reilly, D., An, L. C., Tewari, M., Hanauer, D. A., & Choi, S. W. (2016). User-centered design groups to engage patients and caregivers with a personalized health information technology tool. *Biology of Blood and Marrow Transplantation*, *22*(2), 349–358. https://doi.org/10.1016/j.bbmt.2015.08.032

Mayhew, D. J., & Mantei, M. (1994). A basic framework for cost-justifying usability engineering. In R. G. Bias & D. J. Mayhew (Eds.), *Cost-justifying usability* (pp. 9–43). Academic Press.

Mao, J. Y., Vredenburg, K., Smith, P. W., & Carey, T. (2005). The state of user-centered design practice. *Communications of the ACM*, *48*(3), 105–109. https://doi.org/10.1145/1047671.1047677

McCormick, M. E., Ward, E., Roberson, D. W., Shah, R. K., Stachler, R. J., & Brenner, M. J. (2015). Life after tracheostomy: Patient and family perspectives on teaching, transitions, and multidisciplinary teams. *Otolaryngology–Head and Neck Surgery*, *153*(6), 914–920. https://doi.org/10.1177/0194599815599525

McKnight, C., Dillon, A., & Richardson, J. (1996). User centered design of hypertext and hypermedia for education. In D. Jonassen (Ed.), *Handbook of research on educational communications and technology* (pp. 622–633). Macmillan.

McNamara, D. G., Dickinson, A. R., & Byrnes, C. A. (2009). The perceptions and preferences of parents of children with tracheostomies in a study of humidification therapy. *Journal of Child Health Care*, *13*(3), 179–197. https://doi.org/10.1177/1367493509336686

McPherson, M. L., Shekerdemian, L., Goldsworthy, M., Minard, C. G., Nelson, C. S., Stein, F., & Graf, J. M. (2017). A decade of pediatric tracheostomies: Indications, outcomes, and long-term prognosis. *Pediatric Pulmonology*, *52*(7), 946–953. https://doi.org/10.1002/ppul.23657

Meltzer, L. J., Boroughs, D. S., & Downes, J. J. (2010). The relationship between home nursing coverage, sleep and daytime functioning in parents of ventilator-assisted children. *Journal of Pediatric Nursing*, *25*(4), 250–257. https://doi.org/10.1016/j.pedn.2009.01.007

Michelson, K. N., Koogler, T., Sullivan, C., del Pilar Ortega, M., Hall, E., & Frader, J. (2009). Parental views on withdrawing life-sustaining therapies in critically ill children. *Archives* *of Pediatrics & Adolescent Medicine*, *163*(11), 986–992. https://doi.org/10.1001/archpediatrics.2009.180

Montagnino, B. A., & Mauricio, R. V. (2004). The child with a tracheostomy and gastrostomy: Parental stress and coping in the home–a pilot study. *Pediatric Nursing*, *30*(5), 373–380, 401.

Nageswaran, S., Golden, S. L., Gower, W. A., & King, N. M. P. (2018). Caregiver perceptions about their decision to pursue tracheostomy for children with medical complexity. *The Journal of Pediatrics*, *203*, 354–360.e1. https://doi.org/10.1016/j.jpeds.2018.07.045

Namachivayam, P., Shann, F., Shekerdemian, L., Taylor, A., van Sloten, I., Delzoppo, C., Daffey, C., & Butt, W. (2010). Three decades of pediatric intensive care: Who was admitted, what happened in intensive care, and what happened afterward. *Pediatric Critical Care Medicine*, *11*(5), 549–555. https://doi.org/10.1097/PCC.0b013e3181ce7427

Nelson, J. E., Kinjo, K., Meier, D. E., Ahmad, K., & Morrison, R. S. (2005). When critical illness becomes chronic: Informational needs of patients and families. *Journal of Critical Care*, *20*(1), 79–89. https://doi.org/10.1016/j.jcrc.2004.11.003

Nelson, J. E., Mercado, A. F., Camhi, S. L., Tandon, N., Wallenstein, S., August, G. I., & Morrison, R. S. (2007). Communication about chronic critical illness. *Archives of Internal Medicine*, *167*(22), 2509–2515. https://doi.org/10.1001/archinte.167.22.2509

October, T. W., Fisher, K. R., Feudtner, C., & Hinds, P. S. (2014). The parent perspective: "Being a good parent" when making critical decisions in the PICU. *Pediatric Critical Care Medicine*, *15*(4), 291–298. https://doi.org/10.1097/PCC.0000000000000076

October, T. W., Jones, A. H., Greenlick Michals, H., Hebert, L. M., Jiang, J., & Wang, J. (2020). Parental conflict, regret, and short-term impact on quality of life in tracheostomy decision-making. *Pediatric Critical Care Medicine*, *21*(2), 136–142. https://doi.org/10.1097/PCC.0000000000002109

Rane, S., Shankaran, S., & Natarajan, G. (2013). Parental perception of functional status following tracheostomy in infancy: A single center study. *The Journal of Pediatrics*, *163*(3), 860–866. https://doi.org/10.1016/j.jpeds.2013.03.075

Riis, J., Loewenstein, G., Baron, J., Jepson, C., Fagerlin, A., & Ubel, P. A. (2005). Ignorance of hedonic adaptation to hemodialysis: A study using ecological momentary assessment. *Journal of Experimental Psychology: General*, *134*(1), 3–9. https://doi.org/10.1037/0096-3445.134.1.3

Ritter, F. E., Baxter, G. D., & Churchill, E. F. (2014). User-centered systems design: A brief history. In F. E. Ritter, G. D. Baxter, & E. F. Churchill (Eds.), *Foundations for designing user-centered systems: What system designers need to know about people* (pp. 33–54). Springer. https://doi.org/10.1007/978-1-4471-5134-0_2

Roscigno, C. I., Savage, T. A., Kavanaugh, K., Moro, T. T., Kilpatrick, S. J., Strassner, H. T., Grobman, W. A., & Kimura, R. E. (2012). Divergent views of hope influencing communications between parents and hospital providers. *Qualitative Health Research*, *22*(9), 1232–1246. https://doi.org/10.1177/1049732312449210

Schkade, D. A., & Kahneman, D. (1998). Does living in california make people happy? A focusing illusion in judgments of life satisfaction. *Psychological Science*, *9*(5), 340–346. https://doi.org/10.1111/1467-9280.00066

Schneidermeier, T., Maier, F., & Schricker, J. (2013). Human-centered communication planning: a conceptual approach. In A. Marcus (Ed.), *Design, user experience, and usability. Web,* *mobile, and product design* (pp. 94–102). Springer. https://doi.org/10.1007/978-3-642-39253-5_11

Searl, M. M., Borgi, L., & Chemali, Z. (2010). It is time to talk about people: A human-centered healthcare system. *Health Research Policy and Systems*, *8*(1), Article 35. https://doi.org/10.1186/1478-4505-8-35

Shaffer, V. A., Focella, E. S., Hathaway, A., Scherer, L. D., & Zikmund-Fisher, B. J. (2018). On the usefulness of narratives: An interdisciplinary review and theoretical model. *Annals of Behavioral Medicine*, *52*(5), 429–442. https://doi.org/10.1093/abm/kax008

Sharman, M., Meert, K. L., & Sarnaik, A. P. (2005). What influences parents' decisions to limit or withdraw life support? *Pediatric Critical Care Medicine*, *6*(5), 513–518. https://doi.org/10.1097/01.pcc.0000170616.28175.d9

Taylor, D. P., Bray, B. E., Staggers, N., & Olson, R. J. (2003). User-centered development of a web-based preschool vision screening tool. *AMIA Annual Symposium Proceedings*, *2003*, 654–658.

Thyen, U., Kuhlthau, K., & Perrin, J. M. (1999). Employment, child care, and mental health of mothers caring for children assisted by technology. *Pediatrics*, *103*(6), 1235–1242. https://doi.org/10.1542/peds.103.6.1235

Veryzer, R. W., & Borja de Mozota, B. (2005). The impact of user-oriented design on new product development: An examination of fundamental relationships. *Journal of Product Innovation Management*, *22*(2), 128–143. https://doi.org/10.1111/j.0737-6782.2005.00110.x

Weeks, J. C., Cook, E. F., O'Day, S. J., Peterson, L. M., Wenger, N., Reding, D., Harrell, F. E., Kussin, P., Dawson, N. V., & Connors Jr, A. F. (1998). Relationship between cancer patients’ predictions of prognosis and their treatment preferences. *JAMA*, *279*(21), 1709–1714. https://doi.org/10.1001/jama.279.21.1709

Wilfond, B. S. (2014). Tracheostomies and assisted ventilation in children with profound disabilities: Navigating family and professional values. *Pediatrics*, *133*(Suppl. 1), S44–S49. https://doi.org/10.1542/peds.2013-3608H

Wilson, T. D., & Gilbert, D. T. (2003). Affective forecasting. In M. P. Zanna (Ed.), *Advances in experimental social psychology* (Vol. 35, pp. 345–411). Academic Press. https://doi.org/10.1016/S0065-2601(03)01006-2

Wilson, T. D., & Gilbert, D. T. (2005). Affective forecasting: Knowing what to want. *Current Directions in Psychological Science*, *14*(3), 131–134. https://doi.org/10.1111/j.0963-7214.2005.00355.x

Yaneza, M. M. C., James, H. L., James, H. P., Davies, P., Harrison, S., McAlorum, L., Clement, W. A., & Kubba, H. (2015). Changing indications for paediatric tracheostomy and the role of a multidisciplinary tracheostomy clinic. *The Journal of Laryngology and Otology*, *129*(9), 882–886. https://doi.org/10.1017/S0022215115001140

Zeliadt, S. B., Ramsey, S. D., Penson, D. F., Hall, I. J., Ekwueme, D. U., Stroud, L., & Lee, J. W. (2006). Why do men choose one treatment over another? *Cancer*, *106*(9), 1865–1874. https://doi.org/10.1002/cncr.21822

Zhang, J. (2005). Human-centered computing in health information systems. Part 1: Analysis and design. *Journal of Biomedical Informatics*, *38*(1), 1–3. https://doi.org/10.1016/j.jbi.2004.12.002

Conclusion

Using parents and online samples, and qualitative, experimental, and user-centered designs, this dissertation presented three studies to understand and improve parental tracheostomy decision making. It focuses on three major themes: failures to attend to long-term implications in high-stakes medical decisions, the presence of forecasting errors in these decisions, and the potential for narratives to correct these problems.

These themes demonstrate the importance of understanding potential outcomes and likelihood of those outcomes in improving forecasting and decision making. The judgment and decision making field (JDM) has documented how people are biased when predicting future events and outcomes and stated that accurate judgments are crucial for making effective decisions under uncertainty (Arkes, 1991; Mellers et al., 2015; Tversky & Kahneman, 1974; Yates & Curley, 1985). One type of uncertainty is called *epistemic uncertainty*, which involves insufficient knowledge for making accurate judgments and can be reduced by increasing subjective knowledge (Fox & Ülkümen, 2011). However, the JDM literature showed mixed evidence as to whether more knowledge and experience would improve forecasting (Camerer & Johnson, 1991; Tannenbaum et al., 2017). Nevertheless, anticipating future experiences would be important for informed decision making in many health decisions (Callahan et al., 1999; Carey et al., 2006; Janvier et al., 2012; Lantos, 2016). Studies have demonstrated encouraging effects of having more relevant information about future experiences on improving forecasting (e.g., Angott et al., 2013; Shaffer et al., 2016) and our study provided evidence that parents' forecasting accuracy may be improved with such information.

This dissertation extends the literature on forecasting errors in health decisions to pediatric tracheostomy decisions. Most research studies investigated affective forecasting errors in situations where people focused on negative changes in life due to chronic diseases or disability, overestimated their negative feelings, and underestimated their ability to cope (Halpern & Arnold, 2008; Ubel et al., 2001; Ubel et al., 2005). Although this may be true for some families when facing the tracheostomy decisions for their children, we hypothesized that parents might not be well-prepared for challenges and therefore could be underestimating negative impact in the future. As argued by Zeliadt et al. (2006), it is important that patients make their decisions based on their true value and preferences rather than falsely optimistic information.

The dissertation also adds to the literature of narrative-form communication that different types of narratives induce different effects (Shaffer & Zikmund-Fisher, 2013). It shows further evidence that *experience narratives* help reduce forecasting errors by providing future experiences. As narratives in our studies were designed based on the principles that would increase the likelihood of immersion (Shaffer et al., 2018), their success provides support for the usefulness of these principles in developing narratives that would achieve intended effects.

Limitations and Future Research

There are limitations of these studies. The participants included in the first and third studies were limited to parents from a single study site. Although we strove for including parents from diverse backgrounds, most of them were Caucasian and likely had access to substantial resources needed to seek care at the study site and manage a child with complex medical needs. In addition, they offered their own experiences with home care and life in one Midwestern state, but different states and regions may have different regulations, resources, and cultures. The generalizability of the findings and the booklet in diverse populations and different states needs to be further tested. In the future, we hope to conduct feedback collection and usability testing at other sites in the nation.

Moreover, while Chapter 2 demonstrated the potential effect of narratives about challenges affecting the child's and family's quality of life on forecasting and decisions immediately after viewing the narratives, we are unsure about the effect of these narratives if parents were given time (days to months) to consider this decision. A longitudinal study is warranted to investigate whether providing such information would help decision making in real life and increase decision satisfaction in the long run.

In addition, patients who may need a tracheostomy have diverse underlying conditions, yielding a full spectrum of prognosis. Our studies were limited to more devastating cases where the underlying conditions are severe enough to limit patients' quality of life substantially, according to physicians' judgments. Further studies could investigate whether parents of children with less severe cases need the same kinds of information support for decision making.

General Discussion and Future Directions

While the dissertation focused on forecasting errors in pediatric tracheostomy decision making and the importance of understanding long-term implications of these decisions, we speculated that many other factors and issues were also relevant to parents' decision process and outcomes. The following section discusses these potential factors and implications for future research.

Demographic Factors and Life Experiences

Demographic factors and broader life experiences may play a role in parents' tracheostomy decision-making experiences and final decisions. Some attributes are protective while others tend to bring practical and emotional challenges. These factors could compensate for each other and our participant parents strove to make the best decisions based on judgments of their child’s best interest. Future research is warranted to determine the effects of these factors on parents’ decision process and outcomes.

For instance, higher socioeconomic status is associated with higher health literacy (Andrus & Roth, 2002; Stormacq et al., 2019), which is crucial for making effective medical decisions. We learned that some parents with higher socioeconomic status had abundant resources to help them navigate the decision and home care (e.g., ability to find and comprehend research findings, training in special education). Although other parents might not have those resources, as they spent more time caring for their child and obtained information from the internet and clinicians, they could increase their knowledge about their child’s conditions and reduce stress.

Moreover, a supportive network of family, friends, and healthcare professionals is important for parent caregivers to manage the needs of their medically complex child and themselves (Kuster & Merkle, 2004; Rini et al., 2008). We observed that parents who differed in terms of income, marital status, and availability of support could make the same decisions (either tracheostomy or no tracheostomy). Although the final decisions might not be determined by these factors, parents considered them and recognized their influences on decision and caregiving stress.

A majority of the participant parents showed faith in God’s control of these decisions, which could help coping with stress and guide tracheostomy decisions (Nageswaran et al., 2020). Our participant parents’ decisions seemed partly supported by their religious beliefs. While some believed that God meant to let their child survive and move forward with a tracheostomy, some others believed that God would not want to let a tracheostomy placement happen or to prolong their child's suffering.

The Impact of Emotion

Emotion plays an important role in decision making and each emotion may have distinct influences (Lerner et al., 2015). Parents described making tracheostomy decisions and caring for their critically ill child as emotional experiences (Gower et al., 2020; Montagnino & Mauricio, 2004; October et al., 2020). In particular, the literature and our findings found that parents felt stressed and overwhelmed with negative emotions (e.g., sadness, fear, anxiety, anger, guilt) and that some had stress-related disorders such as depression. In the meantime, many parents tried to maintain optimism and hope. Future research can investigate how each emotion (including valence and intensity) affects tracheostomy decision making.

People under stress can make disadvantageous decisions due to decreases in decision-making abilities, use of dysfunctional strategies (e.g., incomplete or disorganized information searching), and bias towards short-term thinking (Starcke & Brand, 2012). Thus, parents may focus on short-term outcomes without having adequate information to understand long-term implications of tracheostomy (discussed as one of the forecasting errors). Moreover, negative emotions can make people avoid or defer decision making (Anderson, 2003) and some of our participant parents showed avoidance to make the tracheostomy decisions initially. Thus, it may be important to help parents make timely decisions to prevent negative consequences due to delays in decision. Psychological support is needed to help parents manage these negative emotions for well-being and better decision making. On the other hand, parents use various coping strategies (Flynn et al., 2013) and maintaining optimism and hope is one of them. Even unrealistic hope can be adaptive (Folkman, 2010), but eventually patients and family need to have more realistic expectations and a balance of hope and the reality (Folkman, 2010; Reder & Serwint, 2009). Therefore, it is essential that clinicians attend to parents' emotional needs and help them digest information.

Cognitive Biases

In addition to the previously-mentioned forecasting errors, there are other relevant cognitive biases to tracheostomy decision making. Future research can investigate how consequential these biases are and how to help parents make informed decisions. For example, the availability heuristic states that people make probability judgments based on how easily specific examples come to mind (Tversky & Kahneman, 1973). Parents may envision their child's outcomes based on the outcomes of a limited number of people they know in real life. They may be heavily influenced by the media, which appears to show more success stories about tracheostomy than challenges or advocacy for palliative care.

In addition, people's judgments and decisions are influenced by whether information is presented in a gain- or loss- frame (Levin et al., 1998; Tversky & Kahneman, 1981), and medical decision making is no exception (Gallagher & Updegraff, 2012; Gong et al., 2013). For instance, the participants were more likely to choose resuscitation than comfort care when the prognostic information was framed as survival data than mortality data (Haward et al., 2008). Therefore, it is crucial for clinicians to understand and avoid biases when communicating information to parents, including using visual aids to reduce framing effects (Garcia-Retamero & Galesic, 2010).

Moreover, people tend to choose the default option, especially when the decision is difficult (e.g., Johnson & Goldstein, 2003). Providers' recommendations and social norm can construct a default option in the context of medical decision making (Huh et al., 2014; Ozdemir

& Finkelstein, 2018). As parents value physicians' recommendations in making end-of-life decisions (Meert et al., 2000) and pediatric intensivists have personal preferences towards life-sustaining treatments (Needle et al., 2012), parents' decisions may be influenced by what clinicians recommend. In addition, parents may tend to choose a socially-desirable option based on their understanding of what good parents should do and what most other parents would do. These issues should be paid attention to during shared decision making.

Implications for Practice

The research presented in this dissertation has several implications for researchers and providers who are interested in promoting informed medical decisions and patient-centered care. First, many medical decisions—such as life support decisions and chronic diseases management—have long-lasting impact on the outpatient life of patients and family caregivers. Therefore, simply informing patients and families about details and short-term benefits and risks of a treatment or procedure may not sufficiently enable them to make informed choices. Life goes on beyond hospital stay. Patients and family caregivers may need information and support to help them anticipate everyday life experiences in a more distant future and prepare for negative outcomes. It is important that providers and researchers understand their needs in this regard and keep this need in mind when discussing and recommending treatment options to patients.

Second, hospital-based providers may not have the time or proper outpatient experiences to discuss such information, but keeping patients and family caregivers informed is a collaborative effort of the health system and support networks (Camosy, 1996). Informal and formal support networks consisting of experienced patients and caregivers can provide tremendous information and emotional support. However, many of them are not well advertised and are difficult to find, especially when patients and caregivers are overwhelmed by having to make a choice. Researchers and providers can serve as a bridge to leverage these resources and connect patients and caregivers with more social support. For instance, in our research, we interviewed parents and summarized their experiences as narratives and recommended support groups for future parents who face the tracheostomy decisions.

Finally, this dissertation has proposed integrating narrative-based interventions into consultations of high-stakes and difficult medical decisions (e.g., the tracheostomy decisions) to improve decision making. The research process illustrated an interdisciplinary team approach, which could also be used for aiding other difficult medical decisions. As researchers and providers should partner with patients and families (when appropriate) to design care plans and support that serve the patients' needs (Robinson et al., 2008), two of the three studies involved actual stakeholders (i.e., parents) along with expertise and help from clinicians, hospital staff, and social scientists. Engaging actual stakeholders in research can be time consuming. However, when there is a lack of understanding of stakeholders' needs and goals, it is worthwhile involving patients, families, surrogate decision makers as well as the team (e.g., hospital- and community-based clinicians, social workers, researchers) in the process of design and development of patient education to ensure accuracy and usability of the materials. It is also conceivable that implementation of any interventions (e.g., the booklet) in clinical settings requires collaborations between researchers and physicians, nurses, social workers, case managers, and other hospital staff.

References

Anderson, C. J. (2003). The psychology of doing nothing: Forms of decision avoidance result from reason and emotion. *Psychological Bulletin*, *129*(1), 139–167. https://doi.org/10.1037/0033-2909.129.1.139

Andrus, M. R., & Roth, M. T. (2002). Health literacy: A review. *Pharmacotherapy*, *22*(3), 282–302. https://doi.org/10.1592/phco.22.5.282.33191

Angott, A. M., Comerford, D. A., & Ubel, P. A. (2013). Imagining life with an ostomy: Does a video intervention improve quality-of-life predictions for a medical condition that may elicit disgust? *Patient Education and Counseling*, *91*(1), 113–119. https://doi.org/10.1016/j.pec.2012.10.015

Arkes, H. R. (1991). Costs and benefits of judgment errors: Implications for debiasing. *Psychological Bulletin*, *110*(3), 486–498. https://doi.org/10.1037/0033-2909.110.3.486

Callahan, C. M., Haag, K. M., Buchanan, N. N., & Nisi, R. (1999). Decision-making for percutaneous endoscopic gastrostomy among older adults in a community setting. *Journal of the American Geriatrics Society*, *47*(9), 1105–1109. https://doi.org/10.1111/j.1532-5415.1999.tb05235.x

Camerer, C. F., & Johnson, E. J. (1991). The process-performance paradox in expert judgment: How can experts know so much and predict so badly. In K. A. Ericsson & J. Smith (Eds.), *Towards a general theory of expertise: Prospects and limits* (pp. 195–217). Cambridge University Press.

Camosy, P. (1996). Patient support networks: Something for everyone. *Journal of Family Practice*, *42*(3), 278–287.

Carey, T. S., Hanson, L., Garrett, J. M., Lewis, C., Phifer, N., Cox, C. E., & Jackman, A. (2006). Expectations and outcomes of gastric feeding tubes. *The American Journal of Medicine*, *119*(6), 527.e11–527.e16. https://doi.org/10.1016/j.amjmed.2005.11.021

Flynn, A. P., Carter, B., Bray, L., & Donne, A. J. (2013). Parents' experiences and views of caring for a child with a tracheostomy: A literature review. *International Journal of Pediatric Otorhinolaryngology*, *77*(10), 1630–1634. https://doi.org/10.1016/j.ijporl.2013.07.020

Folkman, S. (2010). Stress, coping, and hope. *Psychooncology*, *19*(9), 901–908. https://doi.org/10.1002/pon.1836

Fox, C. R., & Ülkümen, G. (2011). Distinguishing two dimensions of uncertainty. In W. Brun, G. Keren, G. Kirkebøen, & H. Montgomery (Eds.), *Perspectives on thinking, judging, and decision making* (pp. 21–35). Universitetsforlaget.

Gallagher, K. M., & Updegraff, J. A. (2012). Health message framing effects on attitudes, intentions, and behavior: A meta-analytic review. *Annals of Behavioral Medicine*, *43*(1), 101–116. https://doi.org/10.1007/s12160-011-9308-7

Garcia-Retamero, R., & Galesic, M. (2010). How to reduce the effect of framing on messages about health. *Journal of General Internal Medicine*, *25*(12), 1323–1329. https://doi.org/10.1007/s11606-010-1484-9

Gong, J., Zhang, Y., Yang, Z., Huang, Y., Feng, J., & Zhang, W. (2013). The framing effect in medical decision-making: A review of the literature. *Psychology, Health & Medicine*, *18*(6), 645–653. https://doi.org/10.1080/13548506.2013.766352

Gower, W. A., Golden, S. L., King, N. M., & Nageswaran, S. (2020). Decision making about tracheostomy for children with medical complexity: Caregiver and healthcare provider perspectives. *Academic Pediatrics*. https://doi.org/10.1016/j.acap.2020.06.004

Halpern, J., & Arnold, R. M. (2008). Affective forecasting: An unrecognized challenge in making serious health decisions. *Journal of General Internal Medicine*, *23*(10), 1708–1712. https://doi.org/10.1007/s11606-008-0719-5

Haward, M. F., Murphy, R. O., & Lorenz, J. M. (2008). Message framing and perinatal decisions. *Pediatrics*, *122*(1), 109–118. https://doi.org/10.1542/peds.2007-0620

Huh, Y. E., Vosgerau, J., & Morewedge, C. K. (2014). Social defaults: Observed choices become choice defaults. *Journal of Consumer Research*, *41*(3), 746–760. https://doi.org/10.1086/677315

Janvier, A., Farlow, B., & Wilfond, B. S. (2012). The experience of families with children with trisomy 13 and 18 in social networks. *Pediatrics*, *130*(2), 293–298. https://doi.org/10.1542/peds.2012-0151

Johnson, E. J., & Goldstein, D. (2003). Do defaults save lives? *Science*, *302*(5649), 1338–1339. https://doi.org/10.1126/science.1091721

Kuster, P. A., & Merkle, C. J. (2004). Caregiving stress, immune function, and health: Implications for research with parents of medically fragile children. *Issues in Comprehensive Pediatric Nursing*, *27*(4), 257–276. https://doi.org/10.1080/01460860490884165

Lantos, J. D. (2016). Trisomy 13 and 18—treatment decisions in a stable gray zone. *JAMA*, *316*(4), 396–398. https://doi.org/10.1001/jama.2016.9470

Lerner, J. S., Li, Y., Valdesolo, P., & Kassam, K. S. (2015). Emotion and decision making. *Annual Review of Psychology*, *66*(1), 799–823. https://doi.org/10.1146/annurev-psych-010213-115043

Levin, I. P., Schneider, S. L., & Gaeth, G. J. (1998). All frames are not created equal: A typology and critical analysis of framing effects. *Organizational Behavior and Human Decision Processes*, *76*(2), 149–188. https://doi.org/10.1006/obhd.1998.2804

Meert, K. L., Thurston, C. S., & Sarnaik, A. P. (2000). End-of-life decision-making and satisfaction with care: Parental perspectives. *Pediatric Critical Care Medicine*, *1*(2), 179–185. https://doi.org/10.1097/00130478-200010000-00017

Mellers, B., Stone, E., Murray, T., Minster, A., Rohrbaugh, N., Bishop, M., Chen, E., Baker, J., Hou, Y., Horowitz, M., Ungar, L., & Tetlock, P. (2015). Identifying and cultivating superforecasters as a method of improving probabilistic predictions. *Perspectives on Psychological Science*, *10*(3), 267–281. https://doi.org/10.1177/1745691615577794

Montagnino, B. A., & Mauricio, R. V. (2004). The child with a tracheostomy and gastrostomy: Parental stress and coping in the home–a pilot study. *Pediatric Nursing*, *30*(5), 373–380, 401.

Nageswaran, S., Banks, Q., Golden, S. L., Gower, W. A., & King, N. M. P. (2020). The role of religion and spirituality in caregiver decision-making about tracheostomy for children with medical complexity. *Journal of Health Care Chaplaincy*, 1–13. https://doi.org/10.1080/08854726.2020.1755812

Needle, J. S., Mularski, R. A., Nguyen, T., & Fromme, E. K. (2012). Influence of personal preferences for life-sustaining treatment on medical decision making among pediatric intensivists. *Critical Care Medicine*, *40*(8), 2464–2469. https://doi.org/10.1097/CCM.0b013e318255d85b

October, T. W., Jones, A. H., Greenlick Michals, H., Hebert, L. M., Jiang, J., & Wang, J. (2020). Parental conflict, regret, and short-term impact on quality of life in tracheostomy decision-making. *Pediatric Critical Care Medicine*, *21*(2), 136–142. https://doi.org/10.1097/PCC.0000000000002109

Ozdemir, S., & Finkelstein, E. A. (2018). Cognitive bias: The downside of shared decision making. *JCO Clinical Cancer Informatics*, *2*, 1–10. https://doi.org/10.1200/CCI.18.00011

Reder, E. A. K., & Serwint, J. R. (2009). Until the last breath: Exploring the concept of hope for parents and health care professionals during a child's serious illness. *Archives of Pediatrics & Adolescent Medicine*, *163*(7), 653–657. https://doi.org/10.1001/archpediatrics.2009.87

Rini, C., Manne, S., DuHamel, K., Austin, J., Ostroff, J., Boulad, F., Parsons, S. K., Martini, R., Williams, S. E., Mee, L., Sexson, S., & Redd, W. H. (2008). Social support from family and friends as a buffer of low spousal support among mothers of critically ill children: A multilevel modeling approach. *Health Psychology*, *27*(5), 593–603. https://doi.org/10.1037/0278-6133.27.5.593

Robinson, J. H., Callister, L. C., Berry, J. A., & Dearing, K. A. (2008). Patient-centered care and adherence: Definitions and applications to improve outcomes. *Journal of the American Academy of Nurse Practitioners*, *20*(12), 600–607. https://doi.org/10.1111/j.1745-7599.2008.00360.x

Shaffer, V. A., Focella, E. S., Hathaway, A., Scherer, L. D., & Zikmund-Fisher, B. J. (2018). On the usefulness of narratives: An interdisciplinary review and theoretical model. *Annals of Behavioral Medicine*, *52*(5), 429–442. https://doi.org/10.1093/abm/kax008

Shaffer, V. A., Focella, E. S., Scherer, L. D., & Zikmund-Fisher, B. J. (2016). Debiasing affective forecasting errors with targeted, but not representative, experience narratives. *Patient Education and Counseling*, *99*(10), 1611–1619. https://doi.org/10.1016/j.pec.2016.04.004

Shaffer, V. A., & Zikmund-Fisher, B. J. (2013). All stories are not alike: A purpose-, content-, and valence-based taxonomy of patient narratives in decision aids. *Medical Decision Making*, *33*(1), 4–13. https://doi.org/10.1177/0272989X12463266

Starcke, K., & Brand, M. (2012). Decision making under stress: A selective review. *Neuroscience & Biobehavioral Reviews*, *36*(4), 1228–1248. https://doi.org/10.1016/j.neubiorev.2012.02.003

Stormacq, C., Van den Broucke, S., & Wosinski, J. (2019). Does health literacy mediate the relationship between socioeconomic status and health disparities? Integrative review. *Health Promotion International*, *34*(5), e1–e17. https://doi.org/10.1093/heapro/day062

Tannenbaum, D., Fox, C. R., & Ülkümen, G. (2017). Judgment extremity and accuracy under epistemic vs. aleatory uncertainty. *Management Science*, *63*(2), 497–518. https://doi.org/10.1287/mnsc.2015.2344

Tversky, A., & Kahneman, D. (1981). The framing of decisions and the psychology of choice. *Science*, *211*(4481), 453–458. https://doi.org/10.1126/science.7455683

Tversky, A., & Kahneman, D. (1973). Availability: A heuristic for judging frequency and probability. *Cognitive Psychology*, *5*(2), 207–232. https://doi.org/10.1016/0010-0285(73)90033-9

Tversky, A., & Kahneman, D. (1974). Judgment under uncertainty: Heuristics and biases. *Science*, *185*(4157), 1124–1131. https://doi.org/10.1126/science.185.4157.1124

Ubel, P. A., Loewenstein, G., Hershey, J., Baron, J., Mohr, T., Asch, D. A., & Jepson, C. (2001). Do nonpatients underestimate the quality of life associated with chronic health conditions because of a focusing illusion? *Medical Decision Making*, *21*(3), 190–199. https://doi.org/10.1177/0272989X0102100304

Ubel, P. A., Loewenstein, G., Schwarz, N., & Smith, D. M. (2005). Misimagining the unimaginable: The disability paradox and health care decision making. *Health Psychology*, *24*(Suppl. 4), S57–S62. https://doi.org/10.1037/0278-6133.24.4.S57

Yates, J. F., & Curley, S. P. (1985). Conditional distribution analyses of probabilistic forecasts. *Journal of Forecasting*, *4*(1), 61–73. https://doi.org/10.1002/for.3980040110

Zeliadt, S. B., Ramsey, S. D., Penson, D. F., Hall, I. J., Ekwueme, D. U., Stroud, L., & Lee, J. W. (2006). Why do men choose one treatment over another? *Cancer*, *106*(9), 1865–1874. https://doi.org/10.1002/cncr.21822

Appendices

Appendix A

Interview Questions, Study 1 (Chapter 1)

1. **[Need]:** How did this decision of whether to have your child undergo a tracheotomy first come up?

Probe: Was it changes in the child's condition? If so, what were those changes?

2a. **[Mode-Who]:**

2a (1)a. Who participated in discussions, in the hospital setting, about whether your child would undergo a trach? For instance, a family member, a healthcare professional, a religious leader, a friend, and/or other parents?

2a (1)b. Why were they included in the discussions about whether your child would undergo a trach?

2a (1)c. Were there any discussions about this decision OUTSIDE the hospital setting? If so, who participated in discussions about making the decision? For example, a family member, religious leader, a friend, and/or other parents?

2a (1)d. Why were they included in the discussions about whether your child would undergo a trach?

2a (2)a. We would like to know where on the physician directed decision / shared decision / parent-family decision spectrum the decision was made? Imagine a line from 0-100, with physician directed decision on the left (0), parent-family decision on the right (100), and shared decision in the middle (50), what number from 0-100 do you think best represent how this decision was made?

2a (2)b. Why did you choose that number?

2b. **[Mode-What/How]**

2b (1)a. During the time the team and family were contemplating the trach, did you consult with other people as to whether to do the trach? For example, other providers, other families.

2b (1)b. Whom in particular did you seek?

2b (1)c. What in particular did you find?

2b (2)a. Did you consult any informational resources as to whether to do the trach? For example, decision aids, web sites or journals, materials?

2b (2)b. What in particular did you seek?

2b (2)c. What in particular did you find?

3. **[Investment]** Next, let’s turn to the efforts you took to make the trach decision. The efforts could include time and other costs.

3a. **[Investment—Time]**

3a (1). How many discussions regarding the trach decision did you have with healthcare professionals (including doctors, nurses, clinical social workers)?

3a (2). How much time in total do you think was spent on the discussions with the healthcare professionals?

3b. **[Investment—Emotions/Stress]**

3b (1)a. What emotions or feelings did you experience during decision making?

3b (2). How difficult was it for you to manage any stress and other unpleasant emotions that might have arisen when you were thinking through the trach decision for your child?

Not Difficult at All / Somewhat Difficult / Highly Difficult / Extremely Difficult

3b (3). What actions did you take to deal with the stress and other unpleasant emotions that arose when you were thinking through the trach decision?

4. [Options] Next, let’s turn to possible options for your child’s condition.

4a. **[Options—Awareness]**

4a (1)a. First, did you feel that there was actually a choice? (Why did you feel that way?)

4a (1)b. Were there any other non-trach option discussed?

4a (2). Sometimes medical professionals use the term “comfort care” to mean medical care that focuses on relieving symptoms, optimizing comfort, and improving quality of life. Was comfort care ever discussed?

4b. **[Options—Discovery/Generation]** As best you can remember, how did this option come up?

U5. [Possibilities] Now let's consider possible ***outcomes*** of pursuing this option, both the positive ("upsides") and negative ("downsides"). Let's talk about upsides first.

U5a. [Possibilities—Specific]

U5a (1). What did you think were the most significant potential "upsides" for this option and why? Upsides would include benefits and hopes.

U5a (2). Which of these upsides was particularly important to you? Why? **[Value]**

U6. [Chances]: Please tell us what **you** saw as the *chances* that each of those upsides for this option would actually happen—either None at All, Very Low, Somewhat Low, Somewhat High, Very High, or Guaranteed.

U6 (1). What did you see as the chance that ______ would actually happen?

U6 (2). When you said _____ (None at All, Very Low, Somewhat Low, Somewhat High, Very High, or Guaranteed), what probability number between 0% and 100% do you think best describes what you meant?

D5. [Possibilities] Now Let's talk about downsides of this option.

D5a. [Possibilities—Specific]

D5a (1). What did you think were the most significant potential "downsides" for this option and why? Downsides would include risks, fears and worries.

D5a (2). Which of these downsides was particularly important to you? Why? **[Value]**

D6. [Chances]: Please tell us what **you** saw as the *chances* that each of those downsides for this option would actually happen—either None at All, Very Low, Somewhat Low, Somewhat High, Very High, or Guaranteed.

D6 (1). What did you see as the chance that _____ would actually happen?

D6 (2). When you said _____ (None at All, Very Low, Somewhat Low, Somewhat High, Very High, or Guaranteed), what probability number between 0% and 100% do you think best describes what you meant?

7. [Value]:

7a (1). What do you think your child's best interest (or goals of care) is in the context of this decision?

Probe: (if the parent hints something different for the child and the family) What do you think your or your family's best interest is in the context of this decision?

7a (2). What does best quality of life for your child mean to you in the context of this decision?

7b (1). Are there any principles that guided you in the making of this decision? If so, what is it?

8. [Tradeoffs] One of the reasons that trach decisions are difficult is that there may not exist a clear and certain "best" option. Often, none of the options is able to satisfy all needs and free from unwanted outcomes. As a result, parents often have to consider tradeoffs between options. What I mean by tradeoffs is that all options have both pros and cons, and one has to give up something in order to get something else.

8a. From your perspective, what are the core tradeoffs of the trach decision?

8b. In the end, how was the final decision made?

9. [Acceptability]: Who were the people—for instance, family members, friends, community members, or health care professionals (colleagues, nurses, social workers)—whose happiness or unhappiness might be influenced by the trach decision for your child? For instance, some relevant people might agree with the decision while some might disagree.

9a. **[Acceptability—How]:**

9a (1)a. In the end, did you feel that there was agreement among everyone involved in the decision? If so, how did that happen?

9a (1)b. If not, how did you deal with the feelings and potential actions of those individuals?

10. [Implementation]: Once the decision was made about whether your child would have a trach, what happened next?

11. [QOL] People have different values and different ways of being a good parent when making these kinds of decision. Some parents want the longest life possible for their child. Some worry more about the quality of their life more than the quantity of their life.

How did your feelings about valuing quality vs quantity of life play a role in the decision?

12. [Regret]

12a. Thinking back, what information did you wish you had gotten or what did you wish you had done for making this decision?

12b. Do you have any regret regarding the final decision? Why?

[Confirmability] The interviewer summarizes the participant's responses to all questions above and asks, "Did I get your story and opinions right? Is there anything that I missed?"

13. Are there other things that informed or influenced this decision that we have not asked about?

Appendix B

Illustrative Quotes, Study 1 (Chapter 1)

Seeking Support (Theme 1)
Information about tracheostomy and home care
Talking to people who have babies who are on a trach was super helpful…how do you dress your babies…and like visually seeing a video of a baby who's been on a trach is not what I expected like, she was like playing and sitting up and hanging out…it's a very realistic viewing of what could happen next…I read the booklet, and then it helped a lot, but I was googling on my phone a lot of different pictures like what this, I didn't understand what the word was so then I googled it and then at the end of the booklet I just decided to YouTube some trach babies. (Case 9) I wish I would've knew more information in the beginning like I did-like I do now. Then I would've felt more comfortable in the beginning…what all comes with it, how you take care of it, how long is he going to have to have it. Just simple stuff because I didn't know anything about it at all. (Case 16)
Emotional support from peer parents
It's more relaxing to see people who have gone through it. Especially people who have like the same problem that led to her trach so they're almost on the same road...There's just no like moms here, there's like no specific group like in the family lounge that like moms with trach babies, like if you wanna stop by or write a letter and leave it in a box for other moms to read even if you don't wanna have a conversation face to face. (Case 9) I really feel strongly about you know having a parent support network that can you know tell you um this is what this is ok if you feel that way you know…And I'm sure that other parents feel that too and I need to have someone to say that it's okay down the road you made the right decision, but they need to hear that from more than just a doctor cause you know the doctors are I respect them but they are very good at going no no no you did. They've gotta hear it from somebody that's been in the trenches. (Case 12)
Stress (Theme 2)
Stressful emotional state
And it it's overwhelming, especially not being in the medical field. Um I was really thrust into learning a whole new language, a whole new system. Um we switched hospitals this is our third hospital with her, so it's been a lot of learning, so just the um…having a really good handle on it um. (Case 11) I will try not to cry…I was devastated…finding out that he wasn't just, you know a preemie baby that he was supposed to…he was going to be a trach baby was even was even harder. It was very scary…and especially since there's you know really no right or wrong…like what to do… (Case 15)
Coping with stress
I see a therapist…actually talking to his dad and making decisions together helps a lot. (Case 7)

I cope with stress by learning more so I just would pour myself into learning more. (Case 11)
Considerations of Options (Theme 3)
Perception of choice
No. I just thought that was what she was supposed to do. There was no choice. (Case 6) I knew there was a choice because I always have a choice with what goes on with him. I mean if I don't want something to happen I know that they can't do it regardless of my decision or not unless it's life threatening to him obviously. (Case 7)
Tradeoffs
Would be uh let's just say convenience for lack of better word because it would be more convenient not to have it um and then the other would just be quality of life and you know sustainability. (Case 12) So I had to give up my ideal of what I felt like [patient's name]'s life should look like. Um I had to give up my idea of what our family will look like…Um I gained an end date of time of like you can go home now so um the time span in the hospital shortened by saying yes to the trach so I gained that um pretty much assurance that were not gonna be living here next year. (Case 13)
Perceptions of Tracheostomy Over Time (Theme 4)
I started crying instantly…And I'm like wow I have to make this decision and I had to put away my fear and think about the comfort…and the best for my son…so I'm like it's something that I didn't want, but it's something that he needed because he can't go around with a tube down his throat. (Case 10) She [a relative who knows something about trach] just couldn't wait to talk to me about it [trach] and I was like no I'm not ready yet because it's not there, we're not there yet it hasn't happened and in fact it was postponed from Monday to yesterday so I, until it actually happened I was still um resisting it um and open to what was going to happen like was he gonna was something cause like things change all the time. (Case 13)
Quality and Length of Life (Theme 5)
Hopes/Goals/Values
So I'm hoping with the trach…she's gonna flourish, she's gonna grow, she's gonna gain weight, she's gonna be able to eat through her mouth properly again and she's gonna be able to experience the same life that I'm giving my other two kids…I mean I'd have to say like the most important one would be a guaranteed airway, but I think the most important one like to me and my like emotional state specifically is like what I want for [patient's name] is to grow as a healthy normal child and I think the playing and the growing is personally my more important thing. (Case 9) The benefits is um…he doesn't have to have a tube down his throat…he can breathe much better…more mobility…It's not permanent. You can still you can still talk. You can still eat. (Case 10)

Perceptions and considerations of best quality of life
Just having a chance to grow and develop to the best of her ability…and thrive as a human being…and develop, you know, as she gets older, however minimal or maximum, that will be. (Case 8) Just comfort and peace with him in any way we can get it…mainly just try to avoid painful situations or try to whatever, will make him not so miserable in life cause he's already had so much. (Case 14)
Perceptions and considerations of survival and length of life
If I'm gonna have a medically fragile child, and I'm going vow to give them the best life and I'm gonna do within reason everything to give them that. So comfort care was never really an option for me (Case 9) We transferred hospitals a couple times, um and our very first hospital who wouldn't treat her heart. Um they offered comfort care for us. But we opted to get a heart surgery and give her chance. (Case 11)
Worries about home care and family's/caregivers' life with tracheostomy
I would say a downside for some people would be the um…you know like when people just look at you. It'll be the shame you know…cause some people are not you know some people are not that strong, so they don't think about what other people think you. But you know for me maybe in maybe in the past but for now it's like who cares. (Case 10) That's the only thing that I'm scared of you know having to deal with it by myself so that's it. And making sure it don't come out I guess. (Case 17)
Worries about child's well-being with tracheostomy
no swimming, no water activities, since we are a beach family you know. And she will not—she will still go to the beach. I'm not going to take that away from her either. But just saying she couldn't swim and, that was pretty much it. (Case 6) Cause I never heard of it and I heard that it's painful so I don't – that's what I hear is that it's painful, I don't know, and plus he has a hard t—he has a big head so. I'm afraid of how it would work and how it would move. (Case 14) Just that he wouldn't be able, he wouldn't be able to be a normal little boy and do normal little boy things with you know, um, a trach…not be able to like run and play. (Case 15)
Faith and Religious Beliefs (Theme 6)
Faith big time, my relationship with Jesus…in Matthew 6 it says like tomorrow has enough worries of its own today, so it's my walk with the Lord um if I didn't have that, no way would I be sane…so many things are not in our control so I was just waiting and seeing…ultimately he wants us to trust him that he's working this out for our good and for his glory so yes a principle of knowing that god's in control and I'm not. (Case 13)

Appendix C

Survey Materials, Study 2 (Chapter 2)

Scenario:

Imagine that you have a newborn baby.

Your baby was born in a hospital close to your home. However, at 12 hours of age, your baby was observed making unusual twitching movements. The doctors suspected these were seizures and started anti-seizure medication.

Doctors placed an endotracheal tube down your baby's mouth and throat and connected it to a breathing machine to support your baby's breathing. Doctors also gave your baby heavy sedation because the tube would be irritating to the throat.

Your baby was transferred to the Children's Hospital by ambulance. An MRI (brain scan) showed clear evidence of brain injury with some areas of previous bleeding in the brain.

3 Weeks Later (Now)

Your baby has been on the breathing machine for the last 3 weeks. Doctors tried to wean your baby off the breathing machine twice, but the attempts were unsuccessful. Therefore, they have to continue to use the breathing machine. Either you or another close family member has been at the bedside of your baby for the last 3 weeks.

Your baby's eyes are closed most of the time. No one is sure if there is any vision at all, with permanent blindness possible. A hearing test shows that deafness is also very likely. Otherwise, your baby looks normal.

Neurology consultants have predicted a very poor outcome. It is extremely unlikely that your baby will ever be able to eat independently, walk, talk, or communicate. However, it is impossible to be absolutely sure.

A Meeting with the Care Team

This morning, you were invited to a family/team meeting to discuss your baby's situation and options.

In the meeting, the doctor who has been involved and directing your baby's care for all 3 weeks presented a big decision to you,

"Since your baby has suffered a significant injury to the brain and is unable to breathe without continued breathing support, there is a 'big decision' to be made soon—whether or not to place a tracheostomy—to enable long-term breathing support.

The reason that we need to make a decision is that the endotracheal tube with the breathing machine is NOT suitable for long-term breathing support. The endotracheal tube is placed through mouth and may cause serious complications to the throat if used for too long.

On the contrary, a tracheostomy would enable placing a breathing tube through the neck, providing a more permanent and safer airway than the endotracheal tube."

The Meeting, Part 2

The doctor goes on to say:

“If we decide **not to place a tracheostomy**, we will need to withdraw current breathing support. You would be able to hold your baby, who may be able to breathe for hours or more. Without the support of the breathing machine, your baby will most likely not be able to stay alive. However, we would make sure throughout this process that:

- your baby is comfortable,
- your baby is not in pain or short of breath, by using medications, and
- your baby could be held by you until the end.

Our **other option is to place a tracheostomy**.

Your baby would have a surgical procedure, under anesthesia, that makes a small hole (tracheostomy) in the throat to allow a long-term connection, via a tracheostomy tube, to the breathing machine. Babies like your baby with severe brain injuries with tracheostomies rely on breathing machine to survive.

With a tracheostomy,

- your baby will be able to be on less sedation and still be comfortable,
- your baby will have lower chances of complications than with an endotracheal tube,
- your baby will likely survive longer, and
- your baby may be able to move around.

In addition,

- You will be able to hold your baby

There are some risks of the surgical procedure, such as:

- bleeding, and
- infection,

but these are rare.

Some babies can go back home with the tracheostomy and breathing machine. However, in order for you to care for a child with a tracheostomy and breathing machine at home:

- You and a 2nd care giver will need to be trained to suction and change the tracheostomy tube

- You and a 2nd care giver will need to be trained to deal with emergencies, such as the tracheostomy tube falling out or blocked
- You will need to ensure that your child is being looked after 24 hours a day, by you, other family members, or a home nurse, if you would like help from professionals. When babies are home on breathing machine, the insurance company will provide for a nurse to be with your baby usually for 12 hours each day
- You will need to accept the responsibilities of caring for a child who will be completely dependent on the breathing machine”

The Meeting, Part 3

The doctor then summarized the major dilemma:

“In order for your 3-week-old baby to survive for longer, your baby will have to have a tracheostomy and a breathing machine, and you will have to deal with all of the challenges that come along with the machine. Without a tracheostomy and a breathing machine, your baby is unlikely to survive for long.”

The doctor continued:

“We know this is a tough decision. There is no right or wrong decision.

We know that some parents feel that their children need to be given every chance, even if it means a long time in the hospital, lots of sedating medications, and a life dependent on a machine. Those parents therefore choose to have the tracheostomy.

We also know that some parents feel that a short life off a machine is better than a longer life on a machine. They therefore choose not to have the tracheostomy.

We will support whatever decision you make.”

Narratives:

Letters from other parents

To help you make your decision, the care team gives you a handout for you to take home and read.

The doctor then says:

“This handout includes letters from other parents who have gone through similar decisions about tracheostomy. We hope that it will help you to better understand what this decision means to your child and your family and to figure out what the best choice is for your child and your family.”

Baby QOL Narratives:

From Michelle's parent

When doctors asked whether I wanted to do tracheotomy for long-term breathing support versus comfort care, I mainly focused on survival. Comfort care means that Michelle might die at some point, and I didn't want to lose my baby. I would feel so much guilt if I didn't do everything to keep my baby alive. I thought I would be a bad parent if I didn't do everything possible.

In addition, I knew that with a tracheostomy, my baby would be more comfortable breathing, and this to me meant better quality of life. At least, in the short term.

After a while, I realized that I should have thought about what quality of life meant to Michelle in the long term... not just now. When she was little, she was just like other children—lying in bed and waiting for diapers to be changed. However, as she grew older, I realized she was different from other children.

It is hard for me to watch her grow up without being able to do much. I never expected that she couldn't play with other kids on the playground and walk for a few minutes on her own. I never expected that she would be connected to the breathing machine for as long as she lived. I would encourage other parents to take these into account when making the decision.

I have a lot of regret because I now think being a "good parent" would have been to choose comfort care. I realize I was thinking about my comfort not hers. She has suffered so much with almost no quality of life. I wish I would have been able to step back and think about the long term and the big picture of her quality of life.

From Robert's parents

When the doctors were discussing the tracheostomy, we thought that not only would our baby live longer, but also that he would be happier and have a more meaningful life. The doctors said they were uncertain about long-term outcomes.

What we've come to realize is that it didn't really change the quality of life as much as we wished. With our son's conditions, he is probably going to stay connected to the breathing support for his whole life. Our son is still alive, but it's still a very difficult and limited life. He seemed more comfortable and sometimes smiled after the tracheostomy. We are able to have more interactions with him. But, we want him to experience more stuff…going to school, making friends, exploring the world on his own. However, the truth is that he will never do those things—the things that make life worth living.

Instead, we are exhausted and live in dread as we go to the hospital over and over again due to complications. Parents should carefully consider this possible reality—limited activities and experiences for the child—when making this decision. We realize now that being a good parent sometimes means letting go. That quality of life does not just mean breathing more comfortably.

Family QOL Narratives:

From Angela's parent

My little girl Angela has a tracheostomy and connection to breathing machine. I was aware that I would have many caring responsibilities, but I have to admit that caring for Angela has been much more overwhelming and complicated than I expected.

Sometimes I feel exhausted. Many emergencies happened in the middle of the night. The tracheostomy tube fell out once. I was so scared. The tracheostomy nurses told me that a tube falling out was common, but I didn't know what to do. I felt that this is my baby, and I can't afford to make a single mistake. I kept telling myself that I am a strong mother and I will do everything for Angela.

Later on, I realized that it is OK for me to feel anxious, scared, overwhelmed, and exhausted. Many other parents have been the same place. It is not easy to take care of a child in this condition. I learned to accept my weaknesses.

My advice for other parents? I hope that you can consider how much you can actually handle and what resources you can get before committing to this decision.

From Michael's parents:

With a tracheostomy and breathing machine, our child needs 24/7 care. It has been a challenge, which we had not thought about much when making the decision.

It is really important to consider whether you have family or financial resources to take care of your child. You need to have some backup plans.

It is really hard to find good home nurses. Our child has such a special condition, and home nursing is in such high demand, that for a few weeks we couldn't find one. Moreover, some nurses have bad habits, such as putting feet on sofa and spilling food in the microwave. They make us feel uncomfortable.

Often, members of our family have had to stay home to take care of Michael. Sometimes our parents come to help. This is fortunate. Some other families we have talked to have had to sacrifice their jobs to be at home for their child.

Still, our life is pretty isolated. It's almost impossible to visit friends or go outdoors because we need to stay with Michael. In fact, we feel a sense of debt to our other children and our parents. But, the truth is that they have to come second.

Appendix D

15 Forecasting Errors (Phase 1), Study 3 (Chapter 3)

Considerations of Quality of Life

1. Some parents only consider survival and fail to consider other important things.
2. Some parents focus on survival and short-term outcomes, such as benefits and risks of the tracheostomy placement procedure, but fail to consider its long-term implications, e.g., responsibilities of accepting a child who may not function independently.
3. Some parents focus on avoiding the pain of their child passing away soon but underestimate the pain of watching their child grow up without doing much (e.g., cannot speak).
4. Some parents assume having a tracheostomy will mean better long-term quality of life even though that is not always true.
5. Some parents feel that there is always hope of full recovery even though full recovery is sometimes not possible.

Home Care Skills

1. Some parents underestimate the complexity of taking care of a child with tracheostomy.
2. Some parents underestimate the amount and scariness of emergencies when taking care of a child with tracheostomy.
3. Some parents underestimate how long their child will be on tracheostomy and later have a feeling of exhaustion and endlessness.

Material Constraints

1. Some parents fail to consider whether the current home environment is suitable for a child with tracheostomy.
2. Some parents overestimate care support from the community, e.g., public facilities, schools.
3. Some parents overestimate access to and quality of home nurses.
4. Some parents fail to consider uneasiness and troubles of having a stranger (nurse) living in the same house.

Impact on Family Life

1. Some parents underestimate the impact of household income reduction.
2. Some parents underestimate the influence of having a child with tracheostomy on partner and other children in the family.
3. Some parents underestimate the influence of having a child with tracheostomy on their social life.

Appendix E

Booklet Revision Summary (Phase 2), Study 3 (Chapter 3)

	Positive Feedback	Constructive Feedback	Change
Wave 1 Parent Feedback	• Easy to understand • Helpful to know the downsides and risks of tracheostomy • Useful to read about diverse perspectives of quality of life and realistic estimates • Realistic practical challenges • Emphasis on caregivers' needs • Helpful support group information readily available to parents, if used with caution	• Need to emphasize the seriousness of the tracheostomy decision • Explain "technology-dependence," whether it is with or without a ventilator • Reiterate that the decision could be different for different families (the "best interest" section) • Emphasize that the life of parents will change • Emphasize parents' confidence in home care before relying on other resources • Be clear that some poor outcomes are due to the underlying disease, not tracheostomy • Add details such as taking notes during tracheostomy care training, SSI, utility bills, lack of emotional support by family, and perspectives of single parents (income, family support). • Take out "all hospital nurses are nice" • One parent suggested taking out the description of how other people look down on your child, but the other did not.	Added major points in the narrations and details in the narratives

Wave 1 Committee Feedback	• Since there were lots of added details, probe about what can be taken out (especially looks from others) in the next wave.		
Wave 2 Parent Feedback	• Good to lay out pros and cons of tracheostomy and questions parents wonder about during decision making • Diverse perspectives of values • Emphasis on individual choice • Realistic information and summary about challenges • Helpful to have support group information	• Insufficient emphasis on the seriousness of the tracheostomy decision • Emphasize it is 24/7 care • Tell parents to read this booklet with professionals' help • Emphasize the role of palliative doctors for discussing goals of care • Emphasize that tracheostomy alters caregivers' lives • Emphasize difficulties in finding financial and other resources • Add positive aspects of home care nurses, help from the community and family members • Add advice about involving other children in the care plan, finding ways to go out, and consulting with education intervention programs • Add one support group	Added these points wherever appropriate
Wave 2 Committee Feedback	• Keep probing whether to combine the support from school and community narratives.		
Wave 3 Parent Feedback	• Good summary of different aspects of tracheostomy and questions to consider	• More descriptions about insurance types, such as private companies and Medicaid	Added specific points and then generalized as key ideas

	• Good to emphasize individual choice and team support • Inform parents about many important details and advice	• Provide more positive outlook and advice about how to select and work with suitable home care nurses and education intervention programs • Emphasize that confidence and comfort with home care will increase over time • Add details about taking work off, 2nd caregiver not as helpful, home care nurses' behaviors, medical supply companies, social isolation, and challenges going out (cumbersomeness, winter germs) • Add social workers as a resource to find support groups	
Wave 3 Team Feedback	• Since details can be controversial, some details of the narratives have been generalized. • Add descriptions of responsible nurses in the narratives.		
Wave 4 Parent Feedback	• Easy to read • Descriptive, detailed, but at appropriate length • Diverse and fine balanced perspectives • All information is important and real • Powerful narratives • Emphasis on individualized situation • Reading these stories makes	• Some wording suggestions • Add the idea that tracheostomy may not be an option any more as time progresses • Add the idea about training may delay going home • Could be a little more balanced by telling parents that "good nurses could be partners of your child's care."	Changed wording and added points accordingly

	parents not feel alone • Helpful to provide support group information	• Add points about transportation and couples counseling (advice) • Add two support groups	
Wave 4 Committee Feedback	None		