



Home values and experiences navigation track (HomeVENT): Supporting decisions about pediatric home ventilation

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ABSTRACT

Objective: To pilot feasibility and acceptability of HomeVENT, a systematic approach to family-clinician decision-making about pediatric home ventilation.

Methods: Parents and clinicians of children facing home ventilation decisions were enrolled at 3 centers using a pre/post cohort design. Family interventions included: 1) a website describing the experiences of families who previously chose for and against home ventilation 2) a Question Prompt List (QPL); 3) in-depth interviews exploring home life and values. Clinician HomeVENT intervention included a structured team meeting reviewing treatment options in light of the family's home life and values. All participants were interviewed one month after the decision.

Results: We enrolled 30 families and 34 clinicians. Most Usual Care (14/15) but fewer Intervention (10/15) families elected for home ventilation. Families reported the website helped them consider different treatment options, the QPL promoted discussion within the family and with the team, and the interview helped them realize how home ventilation might change their daily life. Clinicians reported the team meeting helped clarify prognosis and prioritize treatment options.

Conclusions: The HomeVENT pilot was feasible and acceptable.

Innovation: This systematic approach to pediatric home ventilation decisions prioritizes family values and is a novel method to increase the rigor of shared decision-making in a rushed clinical environment.

1. Introduction

The population of children in the U.S. who require chronic invasive mechanical ventilation is growing [1,2]. While these patients were once confined to intensive care units, tracheostomy with chronic mechanical ventilation (together referred to here as “home ventilation”) are now readily available to be used at home. The daily care of a child receiving home ventilation is substantial and significantly impacts family life [3-7], yet, data suggest families are unaware of the impact when deciding about this treatment option [8,9]. Decisions about home ventilation often culminate in the neonatal or pediatric intensive care unit (NICU or PICU) where constrained timelines, rapid patient turnover, and frequent clinician changes can make nuanced counseling difficult [10]. Institutional variances

and clinician styles may also influence family counseling about home ventilation [11].

In 2018, we published a framework to systematically and comprehensively approach decisions for or against pediatric home ventilation [12]. We used this framework to design an intervention for families and clinicians, the **Home Values & Experiences Navigation Track (HomeVENT)**. For parents, HomeVENT draws from a balanced, web-based repository of family interviews to describe the experiences of other families across the U.S.—half who chose home ventilation for their child, half who chose alternative options [13,14]. Embedded in the website is a Question Prompt List (QPL) that offers a range of reflective questions that families can choose to ask their child's medical team about home ventilation [15,16]. HomeVENT also includes an assessment of the family's social context and values related to

Abbreviations: QPL, Question Prompt List; NICU or PICU, neonatal or pediatric intensive care unit.

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the home ventilation decision. For clinicians, HomeVENT consists of a structured clinical team meeting to systematically review the child's treatment options considering what is learned about the family's context and values.

The overarching goal of HomeVENT is to offer consistent and comprehensive decision supports for families and clinicians facing a choice about pediatric home ventilation. Here we report on feasibility and acceptability of HomeVENT among families and clinicians in a multicenter pilot study, as well as describe decision-making experiences of those who did and did not receive the HomeVENT intervention.

2. Methods

2.1. Participants

This study was conducted at three geographically diverse pediatric academic medical centers in Maryland, Mississippi, and Washington. Eligible families were English-speaking with a child admitted to the NICU or PICU and were facing a decision about tracheostomy and home ventilation within the next 30 days. One to two parents per child could participate and data were analyzed at the family level. Families received \$50/interview for their participation. Institutional Review Board approval was granted at each site (MD IRB# 00244344; MS IRB# 2020-0178; WA IRB# 00001403) and all waived documentation of written consent. We recruited up to two physicians who participated in the decision about home ventilation for each child.

2.2. Study design

Using a pre/post cohort design, the first five families from each site (N = 15) were enrolled in the Usual Care arm and the final five families per site (N = 15) were enrolled in the Intervention arm (Fig. 1). This study design was intentional to avoid biasing clinicians' approaches to Usual Care families via exposure to the intervention in advance. Usual Care encompassed clinical teams at each site providing family counseling and engaging in home ventilation decision-making at the discretion of the on-service ICU clinician(s). While each center had some elements of counseling and decision-making that they provided most patients, none had a comprehensive, systematic approach.

2.3. Family intervention: Website, question prompt list, interview

All elements of the family intervention are designed to help families explore what their long-term day-to-day experience might be with home ventilation. At enrollment, families received the link to www.Family-Reflections.com, the website synthesizing information from parents across the U.S., half who chose for and half who chose against this technology for their child [14]. Intervention families were encouraged to review all 6 website modules (Table 1). They also received electronic and paper copies

Table 1
Family-to-family website.

Family-to-family website	
Modules	Submodules
Considering treatment options	Trach and vent Other options
Your child's experience	Quality of life Life with the breathing machine
Life at home	New routines & challenges Balancing work, time & money
Relationships	Changes & challenges Extended family & other support
If your child's life is short	Focusing on what is most important Preparing for the end of life
Talking with the medical team	Getting clear about treatment options Expressing your preferences & concerns

of the QPL with questions directly informed by website content (Supplementary File). Families could review the website, and use the QPL, as often as they wished.

Finally, families completed an in-depth, audio-recorded HomeVENT Family Interview, exploring their home life and values related to the home ventilation decision. The interview guide was modeled on www.Family-Reflections.com module content. A summary of the transcribed HomeVENT Family Interview was then created to share with the child's clinicians in the Structured Team Meeting, which discussed family understanding of home ventilation, familial values, and family-specific facilitators & barriers of home ventilation (below).

2.4. Clinician intervention: Structured team meeting

When an Intervention family enrolled, study staff arranged a Structured Team Meeting of interdisciplinary physicians who were key to the child's home ventilation decision. Eligible physicians included those from the ICU, subspecialists, palliative care, and home ventilation team. Study staff facilitated the in-person or virtual meetings via completion of the Structured Team Meeting Guide (Table 2). The Meeting Guide was pre-populated with the summary of the HomeVENT Family Interview, then in real-time prompted team members to review a child's overall prognosis and pros/cons of every respiratory treatment option—including potential transition to end-of-life care— in the context of the family's home life and values.

2.5. Data collection and analysis

2.5.1. Feasibility

Feasibility data tracked for the pilot included time (to complete interventions, to complete study) and participant challenges (accessing materials, completing study procedures). Descriptive analysis was applied.

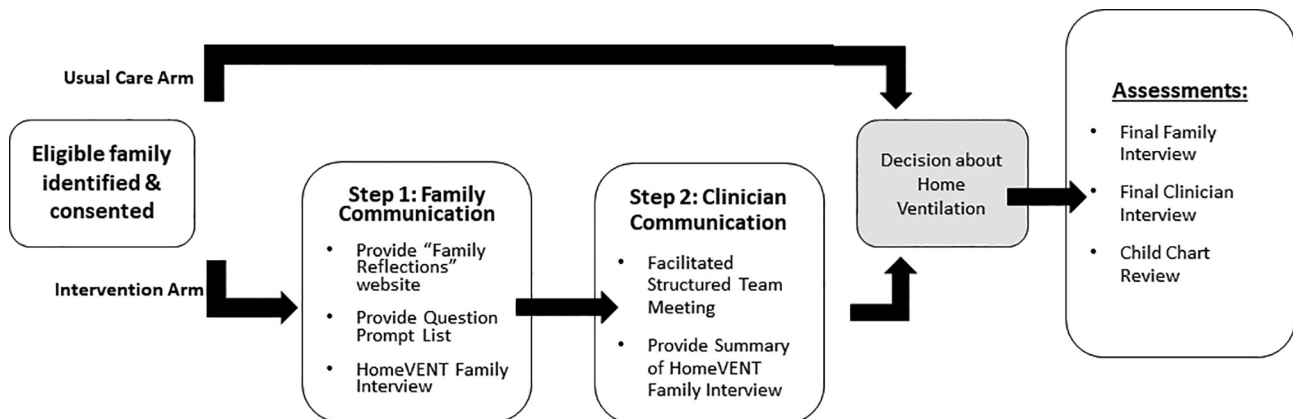


Fig. 1. HomeVENT study design.

Table 2
Summary of structured team meeting guide.

Elements	Key discussion
Achieve consensus about child's prognosis	Short & long-term prognosis [not just respiratory]
Discuss child's likely experience of every treatment option	Tracheostomy, forms of non-invasive ventilation, end of life care, etc.
Hear summary of HomeVENT Family Interview	Family understanding, family values, home ventilation facilitators & barriers
Reconsider clinically viable treatment options, given family context & values	Items needing clarification/ resources prior to finalizing home ventilation decision

2.5.2. Acceptability

All families completed audiotaped, semi-structured Closing Interviews within 30 days after the home ventilation decision. Interview guides were adapted from our prior work [13,14,17] and targeted family perceptions of their decision-making process: adequacy of information, communication with medical teams, weighing options, and factors that helped or hindered their decisions. Intervention families also shared perceptions of the HomeVENT interventions. Acceptability was evaluated through interview questions directly related to acceptability.

All physicians completed audiotaped, semi-structured Closing Interviews within 14 days of the home ventilation decision. The interview guide was developed by the authors and targeted physician perceptions of the decision-making process, awareness of family home life and values, and communication with the family and team. Intervention physicians also shared perceptions of the HomeVENT interventions.

Content analysis [18], facilitated with Dedoose© software [19], was performed on all interview transcripts. Two study team members trained in qualitative data analysis individually assigned codes to a subset of transcripts, then jointly reviewed codes with the larger group to finalize a codebook. One coder coded remaining transcripts, resolving questions iteratively with the larger group. Related codes were grouped into thematic categories, then sorted and organized through repeated discussion. These were consolidated into overarching themes to represent data about home ventilation decision-making and experience with HomeVENT interventions.

3. Results

Between October 2020 and February 2022, we enrolled 30 of 31 approached families representing 30 children with respiratory insufficiency (10 per site), and 34 physicians caring for these children (Table 3). Some eligible families were not approached due to limited time before the decision point. Most physicians were neonatal or pediatric intensivists. Children had a mean age of 23 months and median length of stay of 188 days (Usual Care median 210 days, Intervention median 187 days; 3 were still admitted to hospital at study close). More children in the Usual Care group (14/15) received tracheostomy than in the Intervention group (10/15). Children who did not receive tracheostomy were diverse in ages and medical conditions (Usual Care group diagnosis: prematurity ($n = 1$); Intervention group diagnoses: prematurity ($n = 2$), cardiac anomalies ($n = 1$), severe neurologic injury ($n = 1$), genetic condition ($n = 1$)). Ten children died before hospital discharge (4 with tracheostomy; 6 Usual Care vs. 4 Intervention). Children who died during active ICU treatment (6) vs. those who died after withdrawal of life-sustaining therapies (4) were equally distributed between Intervention and Usual Care groups; most withdrawals occurred during medical crises. Just 2 parents (both in Intervention group) explicitly reported considering (outside of the time of a medical crisis) the option of compassionate extubation or allowing a natural death. Palliative care was involved for half of patients in both groups.

3.1. Feasibility

Enrollment of eligible families across sites was 50–80%; of the families who were approached, 30/31 of families were enrolled. The most common reason why an eligible family was not approached for enrollment was rapid

progression (e.g. a few days) between when the clinical team determined a child might need home ventilation and finalizing a surgical date for tracheostomy. Enrollment of eligible physicians was 100%. Average time from family study enrollment to completion of family and clinician HomeVENT interventions was 8 days and was not reported by clinicians to delay clinical decision-making. No parent reported difficulty accessing the www.Family-Reflections.com website. The time it takes to view the entire website is approximately 1 h. The Intervention families completed the HomeVENT Family Interview which took 40–60 min on average. All physicians and 29/30 families completed the 1-month interview which took 10–15 min. (1 child died before the Closing Interview was completed).

3.2. Intervention acceptability: Family responses

The HomeVENT family intervention included the website, QPL, and HomeVENT Family Interview. The Usual Care families were provided the link to view the website and a paper copy of the QPL for independent viewing. Of these families, 12/15 accessed the website per self-report. These families found it helpful, particularly with reinforcing that different families make different decisions about home ventilation, and in describing family life with the technology. Families who used the QPL (8/15; 7 Intervention and 1 Usual Care) noted it facilitated communication within the family as well as with clinicians.

All Intervention group families participated in the HomeVENT Family Interview; Usual Care families did not participate in any directed interviews. Several described how it helped them reflect on and process how much impact home ventilation would have on their home life (Table 4).

Parent responses during the HomeVENT Family Interview revealed expanded information about their home context and values relevant to the home ventilation decision. In terms of home context, three-quarters had other children and a third had another household member with serious medical problems. A third lived >60 miles from the hospital, a third had no personal vehicle, a quarter were currently struggling to pay bills. Few had considered the potential need for job changes if their child received home ventilation. Though half lived in multilevel homes and two thirds had multiple sets of stairs, a minority thought they might have difficulties moving medical equipment around the house. In terms of values, most families expressed hope that their child's respiratory status would improve, with 3 families specifically hoping for a "miracle". Other common hopes were that the child will grow up 'normal' (5/15) and would get a chance to "be a kid" (4/15). Most families wanted clinicians to prioritize doing what was best for their child; a minority (4/15) wanted to prioritize the child's comfort. Hands-on medical care was the most consistent detractor to their child's quality of life.

3.3. Intervention acceptability: Physician reactions

The physician intervention was the Structured Team Meeting. Most (11/13) found it helpful, especially in helping the team determine whether home ventilation was a reasonable treatment option in light of the 'big picture' (Table 4).

3.4. Usual care vs. intervention groups: Hypothesis-generating comparisons

As described above, intervention feasibility and acceptability were the targeted outcomes of this pilot study. To inform hypothesis-generation for ongoing prospective work, we additionally explored how the Usual Care and Intervention groups compared with regard to family expectations for home ventilation and family-clinician engagement during the home ventilation decision process.

3.4.1. Family expectations regarding home ventilation

In Closing Interviews conducted approximately one month after the home ventilation decision was made, Usual Care families reported that most of what they knew about home life with home ventilation had come from physicians (10/15), hospital-provided materials (7/15) and

Table 3
Family, child and physician characteristics.

EL	Total*	Usual care	Intervention
		Arm	Arm
Family	N = 30	N = 15	N = 15
Mother	29	14	15
Father	13	6	7
Child	N = 30	N = 15	N = 15
Age (mean, months)	23.1	22.7	23.5
Range	(3 mos – 17 years)	(4 mos – 16 years)	(3 mo – 17 years)
Race/ Ethnicity		6 African American 7 White/ non-hispanic 2 Asian	9 African American 6 White/non-hispanic
Reason for hospitalization	Prematurity/Chronic Lung Disease (13) Syndromic condition (9) Cardiac anomalies (4) Severe neurologic injury (2) Other (2)	Prematurity/Chronic Lung Disease (8) Syndromic condition (5) Cardiac anomalies (1) Other (1)	Prematurity/Chronic Lung Disease (5) Syndromic condition (4) Cardiac anomalies (3) Severe neurologic injury (2) Other (1)
Ever been home			
Yes	11	6	5
No	19	9	10
LOS at time of Discharge			
<3 months	6	3	3
3–6 months	8	4	4
>6 months	16	8	8
Tracheostomy			
Yes	25	14	10
No	5	1	5
Disposition at 6 mo from enrollment			
Home	10	6	4
Transfer	5	3	2
Still hospitalized	3	0	3
Died	10	6	4
Respiratory support at discharge/ death			
Tracheostomy/ ventilator	24	14	10
Tracheostomy only	2	0	2
Non-invasive ventilation	3	0	3
None	1	1	0
Physician	N = 34	N = 19	N = 15
Male	15	9	6
Female	19	10	9
Specialty			
PICU/NICU	20	10	10
Pulmonology	5	3	3
ENT	3	1	2
Other**	6	5	1

LOS – Length of Stay.

PICU – Pediatric Intensive Care Unit.

NICU – Neonatal Intensive Care Unit.

ENT – Ear, Nose, Throat (also known as Otolaryngology).

* Both parents of a child were allowed to participate in the HomeVENT Family Interview (Intervention Group) and/or the Closing Interview (Usual Care and Intervention Groups). Any mother or father who participated in at least one interview is counted here.

** Complex Care, Palliative Care.

self-initiated online sources (10/15). Intervention families reported more diverse sources of information, and specifically described learning key information from and about other families via www.Family-Reflections.com (10/15), social media/ other online sources (5/15), or from face-to-face peer-family meetings (2/15).

Parent responses to, “Given where things are now with your child’s health, how do you anticipate that your life at home is going to change?” were grouped by 2 authors (RDB, YD) into positive (“It’s going to be better,” or “We can get back to a normal life,”), neutral (“Just see how we move forward day to day”), or negative (“I will always be on standby”) outlooks. The majority of Usual Care families expected home ventilation to be a positive experience. Intervention families were equally divided between those anticipating a positive (5), neutral (6), or difficult (4) experience with home ventilation.

We haven’t received all the information yet, but we feel we’re pretty prepared to take on all of that stuff. (Family 14, Usual Care)

He’s going to be a fulltime job. It’s hard right now at home, so it’s going to be a lot...not really hard, but just having him at home is going to be a lot of work.

A lot of changes. He’s going to have his own room. We’re trying to make the living room another room for him so we’re not stuck in that room all the time. I don’t know what all we’re going to need yet, but we’re going to try to make sure that we have enough outlets. We got two cribs. One of the cribs got the drawers on so we can keep the supplies right next to him. (Family 3, Intervention)

Describing what ultimately guided their decision about home ventilation, Usual Care families were equally divided between these three reasons: “we exhausted every other option,” “whatever would help the child breathe best” and “whatever will get the child home fastest.” Intervention families described more variable reasons for their decisions, including trying every other treatment possibility first, avoiding surgery, concerns about limiting the child’s mobility, religious/ spiritual beliefs and values regarding quality of life.

3.4.2. Clinician-family engagement

There was evidence of greater physician engagement in the home ventilation decision for Intervention families: 10/18 Usual Care physicians felt they played a primary role in the decision, compared with 15/15

Table 4
HomeVENT Acceptability: Selected quotes from families and physicians.

HomeVENT acceptability: Family responses

Website:
Watching the [website], that helped out a lot with our decisions, with our decision to not get [the trach]. That decisions can be different than anybody else's...for us, I believe that was good to be able to watch videos and hear people talk about it. [Family 7]
I wanted to see what it was about, how to take care of [the trach/ vent]. To hear people's stories about what actually happens when you take them home. [Family 4]

Question Prompt List:
[The QPL] helped me think about what to think about, what to imagine. That helped me process what was going on. I read over the questions, I thought about it for a couple of days, and then it came up in discussion with my husband. I was using the questions to ask him what he thought so we could make a decision together. Then from that, I went back to the questions as a base to ask the doctors in my own words. [Family 8]
I found [the QPL] helpful. I still have the list in my book. A lot of questions are underlined, so I would ask the questions or I would know I need to ask them. I still have that, just in case. [Family 4]

Reflection:
I hadn't been, even with my family, sharing things about [my son]. It's hard when you envision your child to be a normal child, and he's not. That's hard to talk about, especially when he's still a baby. It's good for me, as somebody that doesn't like to talk about things, to talk about it... Talking about what our life is going to look like, it was helpful because it'll look a lot different than it did before. That was helpful. [Family 6]
Y'all made a big difference with me talking to the other doctors...it helped me talk to y'all and go through this process with y'all. It helped me so much. It reminded me of how big of a change it's going to be. I knew it was going to be a big change, but it helped to talk about it. Be like, "Yes, this is a reality. It's going to be huge. Prepare yourself." That was very helpful. [Family 8, Intervention]
I felt like it might have helped [the medical team], just to understand our life a little bit better. [Family 14]

HomeVENT acceptability: Physician responses

Structured Team Meeting:
We felt even more strongly about trying to avoid a trach and vent [after the meeting]. [Clinician 5]
I feel like I know a lot now, more than I did before. With the study, I've learned a lot more about the family and... their home environment, and responsibilities that they have, besides the baby in the hospital. [Clinician 7]
It was positive for this family, realizing that there had been a multidisciplinary discussion. To have a more formal approach than maybe what we normally do with the trach, where providers often individually come by and talk to mom... Often it's more of an impromptu versus a scheduled. I felt it was a more, I don't know if credible is the right word, but a nicer way to give the family more structure and support in helping them come to a decision. [Clinician 13]

Intervention physicians. In both groups, physicians reported their conversations with families about home ventilation were generally impromptu (e.g. during daily rounds). Overall, families reported positive/ respectful/ helpful communication with clinicians. Clinician-only meetings to discuss the option of home ventilation occurred for about a third of children in the Usual Care group. In contrast to the shared mental model described by Intervention group physicians who attended the Structured Team Meetings, Usual Care physicians often described gaps in team communication.

The decision-making process is very decentralized... In general, I think that there is a lack of a system in place for this discussion. It's very ad hoc. Parents are at risk of strong opinions by people who may or may not have the long-term impact of this on the family in the front of their brains. There's an ICU idea of get them out of the ICU, get them home, whatever, then I'll be done. That's not terribly fair to the family... It's not just the tracheostomy. To narrow this to just the tracheostomy decision is unfair to the decision-making the family has to do. (Clinician 14, Usual Care)

4. Discussion and conclusion

4.1. Discussion

This study piloting the HomeVENT process for structured shared decision making about tracheostomy and home ventilation demonstrated feasibility and acceptability at three geographically- and resource-diverse institutions in the U.S. Enrollment was 100% among approached families and physicians, suggesting that decision-making resources are welcome in this clinical context. Not all families in the Intervention group made use of all of the resources (www.FamilyReflections.com, QPL, Family Interview), but those who did consistently found them to be helpful to their own thinking, discussions with loved ones, and working with the medical team to make the home ventilation decision. Physicians in the Intervention group reported the team meeting created a shared mental model between multi-disciplinary team members about the child's prognosis and treatment options in light of the family's context and values.

Shared decision-making is widely endorsed in intensive care settings, especially for high stakes decisions such as home ventilation [20], yet there are very few formal processes in place that account for ICU team structure and are adaptable for family circumstances [21-23]. Because the

decision to proceed with a tracheostomy and home ventilation is often not clinically straight-forward, it is essential to incorporate family context and values. The HomeVENT intervention draws from other clinical areas, like transplant medicine, that systematically incorporate assessments of social context to augment complex clinical decisions [12,24,25]. Multiple aspects of family context which could impact the home ventilation experience were uncovered among Intervention families: caring for other sick family members, living far from the hospital and without a car, lack of awareness of possible parent job disruption, and having no plan for negotiating medical equipment in a multilevel home. A systematic approach to exploring issues like this may reduce bias and promote health equity by making sure that social context is not only discussed for some families during shared decision-making.

The HomeVENT pilot offers several hypothesis-generating findings that warrant study. A majority of Usual Care families cited that their reason for proceeding with home ventilation was "to get home," and their physicians noted that ICU clinicians put a positive spin on "moving through the system" [26]. These may reflect how the fast-paced ICU environment may rank short-term over long-term outcomes, even when the treatment decision is about chronic care. The Usual Care families who only received ICU team counseling reported a narrower, and more positive, understanding of long-term home ventilation. Intervention families had more nuanced, and often more ambivalent, expectations for life at home. Gaps in family expectations of life with home ventilation have been noted in prior studies [8,9,13]. More work is needed to understand how long-term family coping might differ based on expectations prior to discharge.

The introduction of a process that might slow clinical decision-making invokes concern for acceptance and efficiency in ICU settings where length of stay and other quality measures often demand throughput [26]. It is notable that the HomeVENT intervention was very acceptable to clinicians, who felt favorable toward the team meeting. The HomeVENT intervention also tended toward better clinician and family engagement and less conflict between the parties. Opportunities to review the family's social context and the clinical treatment options for the child fostered consensus and a shared mental model between the various care teams, an ideal that is desirable for most ICU clinicians [27].

The ICU patients who are considered for home ventilation are among the sickest hospitalized children with a high degree of medical fragility. Accordingly, it follows that the pre-discharge mortality rate of the patients in

this study was high (33%). Palliative care services were engaged in only half of the children enrolled despite availability at all three centers. While compassionate extubation/ allowing a natural death may not have been a reasonable treatment option for every child in the study, just two of thirty families (both in the Intervention group) reported discussing this possibility. The stakes are high when considering alternatives to home ventilation for a child, underscoring the value of a balanced and complete process to support families and clinicians [20]. While the goal of HomeVENT is not to favor any one decision about home ventilation, but instead to improve the quality of the decision-making process, important next steps include assessing whether HomeVENT's systematic assessment of every treatment option for a child does diversify the actual options chosen.

This was a pilot study designed to evaluate feasibility and acceptability, and as such, has several limitations. It lacks power for extensive comparisons of the Usual care and Intervention groups; the differences highlighted are intended to drive hypothesis-generation for future studies. Families interviewed one month after their decision may have had recall bias or might have been influenced by their child's condition at the time of interview – ie. if the child was not doing well, they may feel negatively about the home ventilation decision even if the two were unrelated. We only enrolled English-speaking families as the intervention website was only available in English; this will be rectified in future work. Internet access (via study-supplied iPads and free hospital wi-fi) was readily available to Intervention families; there is a clear need to make such resources sustainable for ICU families.

4.2. Innovation

Shared decision-making is the gold-standard for high-stakes, preference-sensitive medical decisions; when no one treatment option has a preferred risk: benefit ratio over another, patient/ family preferences are given substantial weight. Yet the literature is replete with evidence that clinician- patient/ family discussions commonly lack the basic elements of shared decision-making: awareness of the decision in question, understanding relevant data, and incorporating patient/ family values [28]. In addition, most tools to promote high-stakes decision-making (e.g. end-of-life decisions) are 1) solely targeted to the patient/ family, and/or 2) presume the decision is being led by a single clinician, and/or 3) presume that clinician is already expert in the decision and relevant data [29].

The HomeVENT pilot study described here is an innovative approach to pediatric shared decision-making on multiple levels. It has components that target families (novel website that provides family-centered information and facilitates exploration of values and preferences) and target clinicians (structured team discussion to jointly review prognosis, possible treatment options, and family values/ preferences). It is designed for the reality of serious inpatient medical decisions and assumes that multiple clinicians are involved and that individual clinicians possess both limited, yet additive, perspectives on the scope of the decision and the relevant data.

4.3. Conclusion

A systematic shared decision-making process regarding pediatric home ventilation was both acceptable and feasible among families and physicians in three independent institutions. Large scale enrollment of families and clinicians is warranted to better evaluate the HomeVENT decision support process.

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Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.pecinn.2023.100173>.

References

- [1] Edwards JD, Houtrow AJ, Lucas AR, et al. Children and young adults who received tracheostomies or were initiated on long-term ventilation in PICUs. *Pediatr Crit Care Med*. 2016;17:e324–34.
- [2] Amimovin R, Aghamohammadi S, Riley C, et al. Analysis of a pediatric home mechanical ventilator population. *Respir Care*. 2018;63:558–64.
- [3] Kirk S, Glendinning C, Callery P. Parent or nurse? The experience of being the parent of a technology-dependent child. *J Adv Nurs*. 2005;51:456–64.
- [4] Ray LD. Parenting and childhood chronicity: making visible the invisible work. *J Pediatr Nurs*. 2002;17:424–38.
- [5] Muesing C, Schimelpfenig B, Hustvet D, et al. Longitudinal prevalence of Tracheostomized children in Minnesota. *Hosp Pediatr*. 2020;10:663–9.
- [6] October TW, Jones AH, Greenlick Michals H, et al. Parental conflict, regret, and short-term impact on quality of life in tracheostomy decision-making. *Pediatr Crit Care Med*. 2020;21:136–42.
- [7] Gonzalez R, Bustinza A, Fernandez SN, et al. Quality of life in home-ventilated children and their families. *Eur J Pediatr*. 2017;176:1307–17.
- [8] Graham RJ, Rodday AM, Weidner RA, et al. The impact on family of pediatric chronic respiratory failure in the home. *J Pediatr*. 2016;175:40–6.
- [9] Meyer-Macaulay CB, Graham RJ, Williams D, et al. “new trach mom Here...”: a qualitative study of internet-based resources by caregivers of children with tracheostomy. *Pediatr Pulmonol*. 2021;56:2274–83.
- [10] Henderson CM, Williams EP, Shapiro MC, et al. “stuck in the ICU”: caring for children with chronic critical illness. *Pediatr Crit Care Med*. 2017;18:e561–8.
- [11] Hebert LM, Watson AC, Madrigal V, et al. Discussing benefits and risks of tracheostomy: what physicians actually say. *Pediatr Crit Care Med*. 2017;18:e592–7.
- [12] Henderson CM, Wilfond BS, Boss RD. Bringing social context into the conversation about pediatric long-term ventilation. *Hosp Pediatr*; 2018.
- [13] Henderson CM, Raisanen JC, Shipman KJ, et al. Life with pediatric home ventilation: expectations versus experience. *Pediatr Pulmonol*. 2021;56:3366–73.
- [14] Boss RD, Henderson CM, Raisanen JC, et al. Family experiences deciding for and against pediatric home ventilation. *J Pediatr*. 2021;229:223–31.
- [15] Lemmon ME, Donohue PK, Williams EP, et al. No question too small: development of a question prompt list for parents of critically ill infants. *J Perinatol*. 2018;38:386–91.
- [16] Yeh JC, Cheng MJ, Chung CH, et al. Using a question prompt list as a communication aid in advanced cancer care. *J Oncol Pract*. 2014;10:e137–41.
- [17] Jabre NA, Raisanen JC, Shipman KJ, et al. Parent perspectives on facilitating decision-making around pediatric home ventilation. *Pediatr Pulmonol*. 2022;57:567–75.
- [18] Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res*. 2005;15:1277–88.
- [19] Dedoose Version 8.3.17, web application for managing, analyzing, and presenting qualitative and mixed method research data. Available at: www.dedoose.com; 2023. Accessed May 2022.
- [20] Kevill K, Ker G, Meyer R. Shared decision making for children with chronic respiratory failure-it takes a village and a process. *Pediatr Pulmonol*. 2021;56:2312–232.
- [21] Kon AA, Davidson JE, Morrison W, et al. Shared decision making in ICUs: an American College of Critical Care Medicine and American Thoracic Society Policy Statement. *Crit Care Med*. 2016;44:188–201.
- [22] Aronson PL, Shapiro ED, Nicolai LM, et al. Shared decision-making with parents of acutely ill children: a narrative review. *Acad Pediatr*. 2018;18:3–7.
- [23] Opel DJ. A 4-step framework for shared decision-making in pediatrics. *Pediatrics*. 2018;142:S149–56.
- [24] Volk ML, Biggins SW, Huang MA, et al. Decision making in liver transplant selection committees: a multicenter study. *Ann Intern Med*. 2011;155:503–8.
- [25] Lewandowski AN, Skillings JL. Who gets a lung transplant? Assessing the psychosocial decision-making process for transplant listing. *Glob Cardiol Sci Pract*. 2016;16(3):e201626.
- [26] Marcus KL, Henderson CM, Boss RD. Chronic critical illness in infants and children: a speculative synthesis on adapting ICU care to meet the needs of long-stay patients. *Pediatr Crit Care Med*. 2016;17:743–52.
- [27] Shapiro MC, Donohue PK, Kudchadkar SR, et al. Professional responsibility, consensus, and conflict: a survey of physician decisions for the chronically critically ill in neonatal and pediatric intensive care units. *Pediatr Crit Care Med*. 2017;18:e415–22.
- [28] Legare F, Whittleman HO. Shared decision making: examining key elements and barriers to adoption into routine clinical practice. *Health Aff*. 2013;32(2):276–84.
- [29] Nayfeh A, Gotlib Conn L, Dale C, et al. The effect of end-of-life decision-making tools on patient and family-related outcomes of care among ethnocultural minorities: a systematic review. *PLoS One*. 2022;17(8):e0272436.