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An acceptability pilot of the facilitating active management in lung illness with engaged surrogates (FAMILIES) study

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Abstract

Approximately half of the surrogate decision makers of critically ill adults are at risk for negative emotional burden. Decision support and effective surrogate-clinician communication buffers against such experiences. The objective of this study is to evaluate the acceptability of a new surrogate-targeted educational tool that promotes engagement with clinicians and advocacy for 2 evidence-based practices in the provision of mechanical ventilation for acute respiratory failure: spontaneous awakening and breathing trials.

A panel of 44 former patients and surrogates of a 20-bed medical intensive care unit in a large academic hospital responded to an online survey. Acceptability was measured on 3 dimensions: attitudes toward the content and delivery of information, objective knowledge translation, and subjective knowledge acquisition.

More than 80% of participants found the tool to be easy to read, and over 90% felt that the tool provided actionable recommendations. A significant number of previously unsure participants were able to identify what spontaneous awakening and breathing trials are and when they occur, and 16% to 36% reported significant improvements in their subjective understanding of the target evidence-based practices, after being exposed to the educational tool.

This line of work seeks to reduce surrogates' negative emotional burden while also promoting quality critical care. The educational tool provides a promising new way to promote surrogate-clinician communication, by increasing surrogates' knowledge about and encouraging advocacy for evidence-based practices in the provision of mechanical ventilation.

Abbreviations: 95% CI = 95% confidence interval, AHRQ = Agency for Healthcare Research and Quality, FAMILIES = facilitating active management in lung injury with engaged surrogates, ICU = intensive care unit, M = mean, PEMAT = Patient Educational Assessment Tool for Printable Materials, SAT = spontaneous awakening trial, SBT = spontaneous breathing trial, SD = standard deviation.

Keywords: acute respiratory failure, communication, evidence-based practice, mechanical ventilation, surrogate decision makers

1. Introduction

There are a number of evidence-based practices that dramatically improve the outcomes of patients receiving mechanical ventilation for acute respiratory failure. As part of the intensive care unit (ICU) liberation bundle, the Society of Critical Care Medicine recommends the regular use of both spontaneous awakening trials (SATs) and spontaneous breathing trials (SBTs).[1–3] Together, SATs and SBTs are associated with shorter duration of mechanical ventilation, reduced weaning time and reintubation rates, fewer complications such as over-sedation and delirium, and decreased ICU and hospital lengths of stay.[4–8] Yet, these recommendations have not been fully integrated into standard practice.[9–13] For example, while the data supporting SATs and SBTs are robust, safety concerns such as patient discomfort or accidental self-extubation continue to be significant barriers to practice.[4–8,11,13–16] Meanwhile, survivors remain at risk for prolonged mechanical ventilation and other ventilator associated events.[17–21]

Patients receiving mechanical ventilation for acute respiratory failure tend to be too critically ill to advocate on their own behalf, requiring that clinicians rely on family members or other types of surrogates as patient representatives. Unfortunately, surrogates' participation in the medical decision-making process puts them at risk for anxiety, stress, doubt, and regret.[22–26] In fact, as many as a third to a half of surrogates experience negative emotional burden that can last for months if not years after a critical care incident.[22,25] Current guidelines recommend that clinicians provide surrogates with information that prepares them for decision-making and caregiver demands. Yet, these recommendations are based on moderate to poor quality evidence, leaving little guidance for exactly what

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information should be conveyed, when, and how.[19,27] Furthermore, little attention has been paid to surrogate experiences with decisions made outside of end-of-life discussions.[28] The current study begins to fill these knowledge gaps by testing the acceptability of a novel educational tool that activates surrogates as advocates for SATs and SBTs to promote weaning from and recovery after mechanical ventilation. The ultimate goal is to more fully engage surrogates as part of the care team; informed and engaged surrogates are less likely to experience negative emotional burden, particularly with regard to decisional doubt and regret.

The facilitating active management in lung injury with engaged surrogates (FAMILIES) study is centered upon an educational tool that was created by integrating communication theory with clinical recommendations for the provision of mechanical ventilation to patients with acute respiratory failure. The first part of the tool orients readers to the ICU by introducing the clinicians who are in charge of managing the ventilator and describing how to reach them. Using the theory of planned behavior as a guide, this section of the tool fosters positive attitudes toward communicating with clinicians by emphasizing surrogates' role in helping to determine goals of care.[29,30] The second part of the tool defines SATs and SBTs, when they typically occur, and which clinicians can provide information about patients' eligibility. A list of questions to help initiate surrogate-clinician communication about SATs and SBTs is provided at the end of the tool. Doing so targets surrogates' efficacy beliefs, by reiterating who is in charge of managing the mechanical ventilator, and how to engage with them about SATs and SBTs. Surrogate-clinician communication about eligibility for SATs and SBTs should promote information exchanges and care goal alignment, thus reducing surrogates' negative emotional burden often associated with underlying uncertainties inherent to the medical decision-making process.[31,32] These discussions also serve as a nudge to remind clinicians to regularly assess patients' eligibilty for SATs and SBTs.

The objective of this study is to pilot the FAMILIES study educational tool. As with any newly developed tool, an important part of the piloting process is to ensure that key stakeholders, particularly the targets of the intervention, are satisfied with and find the tool to be acceptable. The implementation science literature defines acceptability as participants' reactions to the content and delivery of an intervention, including ease of use, intention to act, and knowledge acquisition.[33,34] Accordingly, in the current study acceptability was measured on 3 dimensions: attitudes toward the content and delivery of the tool's information, objective knowledge translation (i.e., did participants learn key takeaways), and changes in subjective knowledge acquisition (i.e., did they feel that they learned something).[35]

2. Materials and methods

2.1. Setting and sample

This observational study evaluated former patients and surrogates of a 20-bed medical ICU housed within a large academic hospital in the Midwest. Participants were recruited through a patient and family engagement program affiliated with the university's hospital. All members over the age of 18 were eligible to participate. Participation was voluntary and the study was approved by the institutional review board.

2.2. Instruments

This acceptability pilot was conducted with an online survey that contained the written educational tool. In preparation for the current study, a Delphi process was used to refine the educational tool and to ensure that the content adheres to current clinical recommendations for SATs and SBTs. Well-respected practicing clinicians including 3 intensivists, 2 registered nurses, 2 respiratory therapists, a clinical pharmacist, and 3 clinical care coordinators participated in the process. After each iteration, adjustments were made to maintain a 7th grade reading-level, which corresponds with the projected average of surrogates.[36] The final version of the tool was scored at a 6.8 grade reading-level using the Microsoft Word version of the Flesch-Kincaid readability test, and was rated at 70.6 out of 100 on the Flesch reading ease test, where greater numbers indicate greater ease; scores over 60 can be understood by most Americans over the age of 15.[37] A supplementary video, http://links.lww.com/MD/D836 that narrates the tool was also created and included for auditory and multi-modal learners.[38] The video was created using online software; words appear as if typed on the screen as the educational materials from the written tool are read aloud using a voice-over.

The survey was built in and administered with Qualtrics, an online survey platform. The first part of the survey captured participants' demographics. No identifying information was collected. The remainder of the survey focused on participants' attitudes and opinions before and after exposure to the written educational materials and supplemental video, http://links.lww.com/MD/D836.

Items capturing attitudes toward the content and delivery of the tool's information were based on the Agency for Healthcare Research and Quality (AHRQ's) assessment for patient educational materials.[36] The 5 items focused on the readability of the tool and whether recommendations for contacting clinicians were actionable (see Table 1). Participants could also respond to open-ended items asking if they had any additional thoughts about the materials.

Objective knowledge translation was captured on 12 items that were created and refined during the Delphi process used to develop the educational tool (see Table 1). The purpose of these items was to determine whether exposure to the tool improved participants' ability to identify SATs and SBTs, when they should occur, and the clinicians responsible for managing the ventilator.

Subjective knowledge was captured with 4 items, which were also created and refined during the Delphi process described above. These items focused on participants' reported understanding of SATs and SBTs, and whether they felt that they knew who to contact to discuss these target evidence-based practices.

2.3. Procedures

Enrollees in the hospital's patient and family engagement program received the survey link via email from a program administrator. This process was used to protect program participants' identities; therefore, response rates are not known. The survey link remained active from April 1st, 2019 to April 15th, 2019.

The first part of the survey captured demographic information. For the remainder of the survey, participants were instructed to imagine that an adult family member or close friend has been admitted to the ICU and placed on mechanical ventilation due to

Table 1

Constructs and survey items.

Construct	Item	Response options
Attitudes toward the content and delivery of information in the tool	The information in the tool helps me know what to talk to the care team* about.	1 (strongly disagree); 2 (disagree); 3 (neither agree nor disagree); 4 (agree); 5 (strongly agree)
	The information in the tool increases the likelihood that I will try to contact my loved one's care team.	1 (strongly disagree); 2 (disagree); 3 (neither agree nor disagree); 4 (agree); 5 (strongly agree)
	The written materials were easy to read.	1 (strongly disagree); 2 (disagree); 3 (neither agree nor disagree); 4 (agree); 5 (strongly agree)
	This was too much information for me.	1 (strongly disagree); 2 (disagree); 3 (neither agree nor disagree); 4 (agree); 5 (strongly agree)
	The video helped me understand the written materials.	1 (strongly disagree); 2 (disagree); 3 (neither agree nor disagree); 4 (agree); 5 (strongly agree)
Objective knowledge translation	Sam has a really bad case of pneumonia. Sam gets sedation medication and is put on a mechanical ventilator. How soon would you expect someone to turn down or stop Sam's sedation medication?	12 h later; 24 h later; 48 h later; I don't know
	Continuing on with the example, Sam has been on a ventilator for 2 days. Sam's nurse comes in and turns down Sam's sedation medication. The nurse tells Sam, "Open your eyes." The nurse holds up two fingers and asks Sam, "How many fingers am I holding up?". The nurse's goal is to see if Sam can follow simple commands. What is that called?	An awakening trial; a breathing trial; a Bonito test; I don't know
	Sam cannot follow the nurse's commands. When is the next time someone should turn down sedation and check if Sam is able to follow simple commands?	12 h later; 24 h later; 48 h later; I don't know
	Continuing on with the previous example, who will know the next time Sam should get an awakening trial?	A registered nurse; the attending physician; A resident; A fellow; Any of the people listed above will know; I don't know
	The next morning, Sam seems alert and is able to follow all of the nurse's commands. What should happen next?	Sam should get an awakening trial; Sam should get a breathing trial; Sam should get a Bonito test; I don't know
	Why are awakening trials important?	They check to make sure the patient is not over-sedated; they allow for a breathing trial to be conducted; they help the patient get off of the ventilator faster; all of the above; I don't know
	When do awakening trials normally happen?	Mornings; afternoons; evenings; multiple times a day; I don't know
	Morgan is on a ventilator due to pulmonary edema, meaning there is too much fluid in the lungs. Morgan's sedation is turned down or off when the respiratory therapist comes into the room and explains to Morgan, "I am going to turn the ventilator down. Let's see how it goes." What is the respiratory therapist getting ready to do?	An awakening trial; a breathing trial; a Bonito test; I don't know
	After 10 minutes, Morgan is not able to breathe and the ventilator is turned back up. When is the next time someone is likely to check on how Morgan does with the ventilator turned down?	12 h later; 24 h later; 48 h later; I don't know
	Who can tell you when Morgan's breathing will be checked again with the ventilator turned down?	A registered nurse; the attending physician; A resident; A fellow; Any of the people listed above will know; I don't know
	Why are breathing trials important?	They check to see if the patient can breathe on their own; They help the patient get off of the ventilator faster; All of the above; I don't know
	When do breathing trials normally happen?	Mornings; afternoons; evenings; multiple times a day; I don't know
Subjective knowledge acquisition	I understand what an awakening trial is.	1 (strongly disagree); 2 (disagree); 3 (neither agree nor disagree); 4 (agree); 5 (strongly agree)
	I know who to talk to about awakening trials.	1 (strongly disagree); 2 (disagree); 3 (neither agree nor disagree); 4 (agree); 5 (strongly agree)
	I understand what a breathing trial is.	1 (strongly disagree); 2 (disagree); 3 (neither agree nor disagree); 4 (agree); 5 (strongly agree)
	I know who to talk to about breathing trials.	1 (strongly disagree); 2 (disagree); 3 (neither agree nor disagree); 4 (agree); 5 (strongly agree)

* The care team was defined for participants as the attending physician and trainees, registered nurses, and respiratory therapists in charge of managing and monitoring the ventilator.

Table 2

Participant demographics.

Variable	Category	n	Percent
Age*	20–30	3	6.98
	31–40	2	4.65
	41–50	6	13.95
	51–60	14	32.56
	61+	18	41.86
Gender	Female	36	81.82
	Male	8	18.18
Ethnicity	White	43	97.73
	Black or African American	1	2.27
Education	Some college or Associate's degree	10	22.73
	Bachelor's degree	16	36.36
	Master's degree	6	13.64
	Doctorate	2	4.55
	Other	10	22.43
Employment	Employed full time	14	31.82
	Employed part time	4	9.09
	Unemployed and not currently looking for work	2	4.55
	Student	1	2.27
	Retired	19	43.18
	Self-employed	1	2.27
	Unable to work	1	2.27
	Other	2	4.55
Marital status	Single (never married)	5	11.36
	Married	30	68.18
	In a domestic partnership	2	4.55
	Divorced	3	6.82
	Widowed	4	9.09
Previous experience with mechanical ventilation	Yes	16	36.36

* Missing for 1 participant.

fluid in their lungs; they (the participants) were to envision acting as their loved one's surrogate. This was approach was implemented to reduce any recall bias from their own experiences. Participants were asked about their communication preferences for engaging with clinicians (see Ervin for more).[39] Next, participants responded to the objective knowledge translation and subjective knowledge assessments to determine their baseline understanding of SATs and SBTs. Following that, participants read the written educational tool and watched the supplemental video, http://links.lww.com/MD/D836, which were embedded in the survey. After exposure to the tool, participants responded to items capturing their attitudes toward the content and delivery of the information presented in the educational tool and supplemental video, http://links.lww.com/MD/D836. Participants then responded to the same objective knowledge translation and subjective knowledge acquisition items as presented prior to exposure to the educational materials. The last set of items were from AHRQ's Patient Educational Assessment Tool for Printable Materials (PEMAT; not reported here but data available upon request). Participants were thanked for their participation and provided the PI's contact information at the end of the survey.

2.4. Data analysis

Data were analyzed using Stata 15 (StataCorp LLC, College Station, TX, USA).[40] In addition to descriptive statistics, non-parametric tests were used to evaluate pre- and post-exposure responses, as described in greater detail below. A post-hoc power analysis for repeated measures with an α of 0.05 and a power of 80% to detect a medium effect size (0.50) revealed that a total of 34 participants would be needed.

3. Results

3.1. Participant characteristics

A total of 44 participants completed the survey. As reported in Table 2, many participants were married white women in their mid-50's, who had received some college education. Despite such homogeneity, this sample is comparable to samples of surrogates drawn in similar contexts.[18] Of the 36% of participants with previous experience with mechanical ventilation, 2 had themselves been placed on ventilators; the 14 remaining had someone from their nuclear family receive mechanical ventilation during past hospitalizations.

For the analyses below, 8 participants were removed because they exited the survey without responding to the key acceptability dimensions: attitudes toward content and delivery of the information in the educational materials, objective knowledge translation, and subjective knowledge acquisition. Missing data from the remaining 36 participants was infrequent and omitted using pairwise deletion. Imputation procedures were not used because accurate effect sizes are needed to prepare for future work evaluating the feasibility of study procedures and efficacy of the tool.

3.2. Attitudes toward content and delivery of information

Cronbach α indicated that the internal consistency of the 5 items was lower than traditional thresholds at 0.67, but item analyses indicated that omitting any item would result in a lower alpha. In fact, findings revealed large and statistically significant associations among items such as "easy to read" and the amount of information provided in the tool ($r=0.49$) and intention to contact the care team ($r=0.45$), and intentions to contact the

Table 3

Means, standard deviations, and Pearson correlations among the attitudes toward content and delivery items.

Attitudes toward content and delivery items	$M \pm SD$	1.	2.	3.	4.
1. The intervention helps me know what to talk to the care team about.	4.61 ± 0.8				
2. The intervention increases the likelihood of trying to contact the care team.	4.33 ± 1.0	0.74			
3. The intervention was easy to read.	4.25 ± 0.9	0.27	0.45		
4. The intervention contained too much information. (Recoded)	4.25 ± 0.7	0.03	0.08	0.49	
5. The video helped with understanding the written materials.	3.80 ± 0.9	−0.27	−0.29	−0.11	0.04

Note. All items were captured on a scale ranging from 1 (strongly disagree) to 5 (strongly agree).
M = mean, SD = standard deviation.

Table 4

Results from McNemar tests evaluating objective knowledge translation.

Item	Pre-exposure response	Incorrect post-exposure n (%)	Correct post-exposure n (%)	n	χ^2 statistic (df)	*P*-value
When most patients will receive their first SAT.	Incorrect	5 (17.2)	24 (82.8)	36	18.62 (1)	.00
	Correct	2 (28.6)	5 (71.4)			
Ability to identify SATs.	Incorrect	1 (5.6)	17 (94.4)	36	17.00 (1)	.00
	Correct	0 (0.0)	18 (100)			
If still sedated, when most patients will receive another SAT.	Incorrect	8 (24.2)	25 (75.8)	36	25.00 (1)	.00
	Correct	0 (0.0)	3 (100)			
What happens after a SAT.	Incorrect	0 (0.0)	2 (10.0)	22	0.20 (1)	1.00
	Correct	3 (13.6)	17 (77.3)			
Which care team member will know about SATs.	Incorrect	6 (46.2)	7 (53.9)	33	2.78 (1)	.09
	Correct	2 (10.0)	18 (90.0)			
When SATs generally happen.	Incorrect	1 (6.7)	8 (53.3)	15	8.00 (1)	.01
	Correct	0 (0.0)	6 (40)			
The importance of SATs.	Incorrect	4 (80.0)	1 (20.0)	27	0.00 (1)	1.00
	Correct	1 (4.5)	21 (95.5)			
Ability to identify SBTs.	Incorrect	0 (0.0)	2 (100)	22	0.20 (1)	.65
	Correct	3 (15.0)	17 (85.0)			
If patients did not do well on initial SBT, when most will receive another SBT.	Incorrect	8 (26.7)	22 (73.3)	35	22.00 (1)	.00
	Correct	0 (0.00)	5 (100)			
Which care team member will know about SBTs.	Incorrect	3 (25.0)	9 (75.0)	30	3.00 (1)	.08
	Correct	3 (16.7)	15 (83.3)			
When SBTs generally happen.	Incorrect	1 (9.1)	10 (90.9)	15	10.00 (1)	.00
	Correct	0 (0.00)	4 (93.3)			
The importance of SBTs.	Incorrect	0 (0.0)	7 (100)	27	0.00 (1)	1.00
	Correct	0 (0.0)	20 (81.5)			

SAT = spontaneous awakening trial, SBT = spontaneous breathing trial.

team and knowing what to talk to them about ($r = 0.74$); P's $< .001$. Response distributions were generally negatively skewed (see Table 3).

Participants were generally positive when responding to open-ended items tasking their general thoughts about the educational tool. One participant stated:

"I thought the video easily went through the packet so audible learners could listen and visual could read. Great questions to have patients and family members think about or ask the team at the end."

When asked about their specific thoughts on the written tool, multiple participants felt that it lacked visual appeal, despite following AHRQ guidelines for formatting the font, bolding, use of call-out boxes, and negative space. Other participants did not like the animatronic voice that was used to narrate the supplemental video, http://links.lww.com/MD/D836. Fortunately, these issues did not appear to undermine the acceptability of the tool and are easily addressed with the use of a graphic designer.

3.3. Objective knowledge translation

Responses to the 12 multiple-choice items were recoded as correct/incorrect, and pre- and post-exposure scores were compared with McNemar tests, which are non-parametric tests intended for matched data collected from small samples. Findings suggest that exposure to the educational tool significantly increased participants' abilities to identify SATs and when they should occur, and when SBTs should occur (see Table 4). The distribution of responses for identifying the importance of SATs and SBTs, and the appropriate clinicians to contact, were not significant; 80% to 95% of participants were able to identify the correct answers both pre- and post-exposure. There was also little evidence of harm (e.g., few participants shifted from correct to incorrect responses as a function of exposure to the tool).

3.4. Subjective knowledge acquisition

The 4 subjective knowledge items were evaluated using Bowker tests, which compare distributions of responses in matched data.

Table 5

Descriptive statistics for subjective knowledge translation.

Item	*M* (SD)		Mean difference (95% CI)	*t*-statistic (df)
	Pre	Post		
I understand what a SATs are.	3.19 (1.2)	4.39 (0.5)	1.19 (0.79–1.59)	6.14 (35)
I understand what SBTs are.	3.29 (1.1)	4.49 (0.5)	1.20 (0.83–1.57)	6.58 (34)
I know who to talk to about SATs.	3.28 (0.9)	4.42 (0.6)	1.13 (0.79–1.48)	6.71 (35)
I know who to talk to about SBTs.	3.51 (0.2)	4.43 (0.5)	0.91 (0.58–1.24)	5.69 (34)

95% CI = 95% confidence interval, *M* = mean, SAT = spontaneous awakening trial, SBT = spontaneous breathing trial, SD = standard deviation.

Table 6

Bowker's test for subjective knowledge: understanding of a spontaneous awakening trial.

Pre-exposure	Post-exposure					
	1.	2.	3.	4.	5.	Total
1. Strongly disagree	0	0	0	2	1	3
2. Disagree	0	0	0	8	2	10
3. Neither agree nor disagree	0	0	0	1	1	2
4. Agree	0	0	0	10	9	19
5. Strongly agree	0	0	0	1	1	2
Total	0	0	0	22	14	36

Table 7

Bowker's test for subjective knowledge: understanding of a spontaneous breathing trial.

Pre-exposure	Post-exposure					
	1.	2.	3.	4.	5.	Total
1. Strongly disagree	0	0	0	1	1	2
2. Disagree	0	0	0	7	2	9
3. Neither agree nor disagree	0	0	0	0	2	2
4. Agree	0	0	0	10	11	21
5. Strongly agree	0	0	0	0	1	1
Total	0	0	0	18	17	35

Findings indicated that a significant number of previously unsure participants felt that they understood what SATs and SBTs were after exposure to the intervention (see Tables 5–9). For example, 13 participants (36%) disagreed or strongly disagreed that they understood what a SAT was the beginning of the study. After exposure to the tool, 10 of those participants agreed, and the remaining 3 participants strongly agreed that they understood. Similarly, with understanding SBTs, 31% moved from disagree or strongly disagree to agree or strongly agree pre- and post-exposure to the tool. Regarding clinician interaction, 22% moved from being previously uncertain (i.e., disagreeing or strongly disagreeing that they knew who to talk to) about SATs to certain (agreeing or strongly agreeing) post-exposure to the tool, and 17% moved from uncertain to certain with regards to inquiries about SBTs. Importantly, none of the participants felt less certain as a function of being exposed to the educational tool.

Table 8

Bowker test for subjective knowledge: understanding who to ask about spontaneous awakening trials.

Pre-exposure	Post-exposure					
	1.	2.	3.	4.	5.	Total
1. Strongly disagree	0	0	0	0	2	2
2. Disagree	0	0	1	4	1	6
3. Neither agree nor disagree	0	0	0	6	2	8
4. Agree	0	0	0	9	11	20
5. Strongly agree	0	0	0	0	0	0
Total	0	0	1	19	16	36

Table 9

Bowker test for subjective knowledge: understanding who to ask about spontaneous breathing trials.

	Post-exposure					
Pre-exposure	**1.**	**2.**	**3.**	**4.**	**5.**	**Total**
1. Strongly disagree	0	0	0	0	1	1
2. Disagree	0	0	0	5	0	5
3. Neither agree nor disagree	0	0	0	3	3	6
4. Agree	0	0	0	12	9	21
5. Strongly agree	0	0	0	0	2	2
Total	0	0	0	20	15	35

4. Discussion

The overarching goal for the FAMILIES study is to fulfill 2 needs with 1 deed— to use an educational tool encouraging surrogate-clinician communication about eligibility for SATs and SBTs to reduce surrogates' negative emotional burden while promoting best-practices in mechanical ventilation for patients suffering from acute respiratory failure. As a first step toward this end, the current study evaluated how a panel of former patients and surrogates would respond to this newly developed tool.

Overall, findings support the acceptability of the FAMILIES study tool. While minor changes were suggested regarding the delivery of information, participants found the tool to be easy to read, as well as helpful in determining which clinicians are responsible for managing mechanical ventilators and how to engage them. Participants' knowledge significantly improved as a function of being exposed to the educational tool. Finally, there was little evidence of harm, in that exposure to the tool did not reduce participants' objective or subjective understanding of the clinical situation.

This study is not without limitations. The small homogeneous sample makes it difficult to generalize, and some items were underpowered due to variable response rates. It is also worth noting that all participants had recent experiences with a hospitalization, and 36% with mechanical ventilation specifically. Yet, effect sizes for objective and subjective knowledge translation and acquisition were quite robust. Arguably those without the knowledge and experiences from a previous hospitalization have an even greater potential for learning to take place. The next section describes several steps that build upon the current study's findings.

5. Conclusions and future directions

The next step is to conduct a feasibility trial evaluating the practicality of recruiting and randomizing surrogates to an intervention arm or usual care, and the delivery of the study's materials in the ICU. Our ultimate goal is to determine whether and how to tailor the tool to successfully implement it within and across academic and community-based hospitals to improve the experiences of surrogates and the outcomes of the patients that they represent. We are also optimistic about the potential for adapting the FAMILIES study framework to other types of evidence-based practices.

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