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Natalie C. Ernecoff, MPH ^a, Holly O. Witteman, PhD ^{b,c,d}, Kristen Chon ^e, Yanquan (Iris) Chen, MS ^e, Praewpannarai Buddadhumaruk, MS, RN ^f, Jared Chiarchiaro, MD ^f, Kaitlin J. Shotsberger, MSN, RN ^g, Anne-Marie Shields, MSN, RN ^f, Brad A. Myers, PhD ^e, Catherine L. Hough, MD, MSc ^h, Shannon S. Carson, MD ⁱ, Bernard Lo, MD ^j, Michael A. Matthay, MD ^k, Wendy G. Anderson, MD, MS ^l, Michael W. Peterson, MD ^m, Jay S. Steingrub, MD ⁿ, Robert M. Arnold, MD ^o, Douglas B. White, MD, MAS ^{f,*}

- ^a Department of Health Policy and Management, Gillings School of Global Public Health, University of North Carolina, Chapel Hill, NC
- ^b Department of Family Medicine and Emergency Medicine, Laval University, Quebec City, Quebec, Canada
- ^c Office of Education and Continuing Professional Development, Faculty of Medicine, Laval University, Quebec City, Quebec, Canada
- ^d Research Centre of the CHU de Québec, Quebec City, Quebec, Canada
- ^e Human-Computer Interaction Institute, Carnegie Mellon University, Pittsburgh, PA
- f Clinical Research, Investigation, and Systems Modeling of Acute Illness (CRISMA) Center, Department of Critical Care Medicine, University of Pittsburgh School of Medicine, Pittsburgh, PA
- g Office of Healthcare Quality Improvement, Saint Clair Hospital, Pittsburgh, PA
- ^h Division of Pulmonary and Critical Care, Harborview Medical Center, University of Washington, Seattle, WA
- ¹ Division of Pulmonary and Critical Care Medicine, University of North Carolina School of Medicine, Chapel Hill, NC
- ^j The Greenwall Foundation, New York, NY
- k Departments of Medicine and Anesthesia, Cardiovascular Research Institute, University of California San Francisco, San Francisco, CA
- Department of Medicine and Division of Hosiptal Medicine and Palliative Care Program, University of California San Francisco, San Francisco, CA
- m Department of Medicine, University of California San Francisco Fresno Medical Education Program, Fresno, CA
- ⁿ Division of Pulmonary and Critical Care Medicine, Baystate Medical Center, Springfield, Massachusetts and Tufts University School of Medicine, Boston, MA
- ° Division of General Internal Medicine, University of Pittsburgh, Pittsburgh, PA

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ABSTRACT

Purpose: Although barriers to shared decision making in intensive care units are well documented, there are currently no easily scaled interventions to overcome these problems. We sought to assess stakeholders' perceptions of the acceptability, usefulness, and design suggestions for a tablet-based tool to support communication and shared decision making in ICUs. *Methods*: We conducted in-depth semi-structured interviews with 58 key stakeholders (30 surrogates and 28 ICU care providers). Interviews explored stakeholders' perceptions about the acceptability of a tablet-based tool to support communication and shared decision making, including the usefulness of modules focused on orienting families to the ICU, educating them about the surrogate's role, completing a question prompt list, eliciting patient values, educating about treatment options, eliciting perceptions about prognosis, and providing psychosocial support resources. The interviewer also elicited stakeholders' design suggestions for such a tool. We used constant comparative methods to identify key themes that arose during the interviews.

Results: Overall, 95% (55/58) of participants perceived the proposed tool to be acceptable, with 98% (57/58) of interviewees finding six or more of the seven content domains acceptable. Stakeholders identified several potential benefits of the tool including that it would help families prepare for the surrogate role and for family meetings as well as give surrogates time and a framework to think about the patient's values and treatment options. Key design suggestions included: conceptualize the tool as a supplement to rather than a substitute for surrogate-clinician communication; make the tool flexible with respect to how, where, and when surrogates can access the tool; incorporate interactive exercises; use video and narration to minimize the cognitive load of the intervention; and build an extremely simple user interface to maximize usefulness for individuals with low computer literacy.

Conclusion: There is broad support among stakeholders for the use of a tablet-based tool to improve communication and shared decision making in ICUs. Eliciting the perspectives of key stakeholders early in the design process yielded important insights to create a tool tailored to the needs of surrogates and care providers in ICUs.

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E-mail address: whitedb@upmc.edu (D.B. White).

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^{*} Corresponding author at: Program on Ethics and Decision Making in Critical Illness, University of Pittsburgh School of Medicine, Department of Critical Care Medicine, 3550 Terrace St. Scaife Hall, Room 608, HPU010604, Pittsburgh, PA 15261.

1. Introduction

Three decades of research have documented serious shortcomings in how clinicians and surrogates communicate [1–7], such as frequent misunderstandings by surrogates about prognosis [8,9], omission of conversations about patients' values and preferences [10], and inadequate explanation of available treatment options, including palliative care [11,12]. These breakdowns in communication contribute to three major problems: care that is not consistent with patients' values [13,14], lasting psychological distress among surrogates [15–17], and rising costs of end-of-life care [18,19]. The public health impact of these problems is substantial, because it is estimated that more than 500,000 Americans die in intensive care units (ICUs) annually [20].

Although problems with communication between surrogates and clinicians are well documented, there are no evidence-based, easily disseminated interventions to overcome them. In addition, recent research indicates that surrogates want to learn about prognosis and treatment options outside physician encounters to support communication [21]. Several studies suggest that involvement of palliative care or ethics consultants may improve outcomes [22,23]. However, these interventions are difficult to scale up due to projected palliative care workforce shortages and the high costs of adding new staff to ICUs [24-27]. An alternative strategy to address the problem is to use support tools to aid communication and decision making between surrogates and clinicians in the ICU. Use of decision support tools among patients in a variety of clinical setting has been found to increase knowledge, decrease decisional conflict, and help people make more values-congruent decisions [28–32]. Advantages of electronic decision support tools include relatively easy scalability and modification—such as adding content—that would otherwise be difficult and expensive for in-person interventions. However, no tool has been developed for the ICU environment that could be useful to surrogates facing stressful decisions longitudinally over the course of a patient's stay.

We therefore sought to explore key stakeholders' perceptions of an interactive tablet-based and video-driven communication and decision support tool to aid both surrogates and clinicians in ICUs by allowing surrogates to interact with the tool and clinicians to view surrogates' inputs. We conducted semi-structured interviews with surrogates, physicians, nurses, social workers, and spiritual care providers to (1) determine acceptability and perceived usefulness of a webenabled, tablet-based support tool and (2) elicit suggestions for refinements in its design.

2. Methods

2.1. Study design

We conducted one-on-one in-depth, semi-structured interviews with 30 surrogates, 8 physicians, 15 nurses, 3 spiritual care providers, and 2 social workers at the University of Pittsburgh Medical Center between March 2013 and September 2013.

2.2. Participants and Enrollment

Participants were recruited from the medical intensive care unit at the University of Pittsburgh Medical Center, Presbyterian Hospital in Pittsburgh, Pennsylvania. Surrogates met inclusion criteria if they were 18 years or older, able to give full informed consent, able to complete a written questionnaire in English without the help of an interpreter, and self-identified as being involved in surrogate decision making for a patient with: lack of decision making capacity, respiratory failure requiring mechanical ventilation, acute lung injury by conventional criteria [33], and an APACHE II score of 25 or higher signifying at least 50% chance of in-hospital mortality. Surrogates provided feedback either during their loved ones' hospital stays or at three

months post-patient-discharge. We recruited a convenience sample of physicians, nurses, social workers, and spiritual care providers who cared for ICU patients and surrogates.

We enrolled a convenience sample of participants who met the eligibility criteria. Study coordinators identified eligible patients by screening daily in the medical ICU. Prior to approaching potential surrogates, the study coordinator confirmed patient eligibility based on the above stated criteria and obtained permission from the primary attending physician.

All participants provided written informed consent prior to the initiation of any research procedures. Surrogates received \$20 remuneration and care providers received \$10 remuneration for their time. The institutional review board at the University of Pittsburgh approved all study procedures.

2.3. Theoretical framework informing the tool

The tool is grounded in the Cognitive Emotional Decision Making (CEDM) framework, the Ottawa Decision Support Framework, and empirical research on systems-level barriers to clinician-family communication [28,34–39]. Expanding on the traditional decision aid model [40,41], the broad goal of the tool is to promote effective communication and shared decision making between clinicians and patients' surrogates, as delineated in a framework developed by Charles et al. [42], further specified for the ICU environment in existing practice recommendations for family support in ICUs [43–49].

2.4. Development and description of preliminary version of tool

To design a preliminary version of the tool to guide discussions with key stakeholders, we assembled a multidisciplinary expert panel with expertise in communication and decision making in the ICU setting, palliative medicine, ethics, user-centered design, and human-computer interaction. The expert panel identified several contextual considerations of the ICU environment that needed to be accommodated in design of the tool: 1) surrogates are often emotionally overwhelmed and may struggle to engage for prolonged periods with a tool; 2) patients in ICUs have diverse medical conditions, and the tool should be designed to be broadly applicable, rather than tailored to a single disease process; 3) surrogates face a broad range of decisions over time for each patient, and hence the tool should not be focused on a single discrete decision and instead should be focused on helping families function effectively in the role of surrogate decision makers; 4)there is often substantial prognostic uncertainty and a paucity of the kind of high level evidence that would allow formal presentation of risk information in the tool; therefore an alternative strategy is needed to promote effective communication about prognosis rather than simply presenting prognostic estimates. Taking these complexities into consideration, we conceptualized a tool to: 1) prepare the family for conversations with clinicians, 2) give clinicians tailored information about the family and patient in advance of the family meeting, 3) promote a personalized relationship between clinician and family, and 4) provide general decision support to surrogates.

Table 1 summarizes the preliminary sections of the tool, developed by the expert panel to guide discussion with key stakeholders. The tool is designed to be used by surrogates longitudinally over the course of the ICU stay, with sections tailored to different stages of communication and decision making. In addition, important information is summarized in a one-page summary sheet that is provided to the surrogates and the treating physician (i.e. surrogates' main questions and concerns; their perceptions of the patient's prognosis; and their perceptions of the patient values and preferences). The sections of the tool for surrogates are: 1) orienting surrogates to the ICU, 2) explaining principles of surrogate decision making 3) providing a question prompt list and opportunity to write down questions, 4) a values clarification exercise

5) education about treatment pathways (e.g., life prolonging treatment, comfort-focused treatment; and a time-limited trial of ICU care); 6) eliciting surrogates prognostic information, and 7) providing psychosocial resources.

2.5. Study procedures

A researcher trained in semi-structured interviewing techniques conducted all interviews either in a private room adjacent to the ICU or by telephone. The interview guide began with open-ended questions about the participants' perceptions of what general things would be

useful to know in the first few days in the ICU as a surrogate decision maker for an incapacitated patient. The interviewer then described the attributes of the planned tool, explaining the overall goals and general approach followed by an opportunity for the interviewee to ask questions. Then, the interviewer described and elicited feedback on the following potential elements of the tool: orientation to the ICU, education about the surrogate role, completing a question prompt list, eliciting patient values, education about treatment options, eliciting and sharing perceptions about prognosis, and providing psychosocial support resources. Interviewees were asked to provide a binary response as to whether they found each of seven content domains

Table 1Perceived usefulness for each of seven domains of the communication and shared decision making support tool

Domain of Surrogate Support	Approval Rating N = 58 n (%)	Qualitative Themes	Exemplars
Orient surrogates to ICU	58 (100)	Promote surrogate well-being through self-efficacy. Provide ICU-specific education materials (e.g. orientation to the equipment, staffing, and visiting hours) Provide information about logistics and physical space (e.g. hospital and neighborhood maps, cafeteria hours, and information about accommodations)	"and improve just certain basic procedures and things that, I think, can be intimidating and frightening to experience if you aren't prepared." - physician "an orientation would have helped because it kind of did freak me out that it was a little more serious than the usual" -surrogate "we become used to it and forget that it's a very foreign and intimidating environment and for many of our patients' families, a once in a lifetime experience." -physician
Explain surrogate decision making principles	58 (100)	Clarify the concepts to prepare surrogates for decision making Alleviate fear of decision making Improve patient-centered outcomes Clarify surrogate decision maker role Address goals of care with respect to life sustaining treatment	"You just don't know until it's presented to you that you have to make these decisions." –surrogate "Give them permission to say, 'This is what he would want.' Often people are afraid to actually make that statement out loud." –physician "Make it clear that we're not asking for their judgment, but to be the voice of the patient." –physician
Provide question prompt list	58 (100)	Provide question prompt list because stress impairs surrogates' abilities to think clearly and formulate questions Provide question prompt list because surrogates often do not know what questions to ask, and the question prompt list can inform questions Prompt surrogates' memories Aid both surrogates and care providers Empower surrogates to communicate with care providers Provide care providers access to the surrogates' annotated question prompt list prior to a family meeting to prepare care providers and orient them to the family's concerns	"I wouldn't know what questions to ask. I would just be out of it" – surrogate "Sometimes you're just so tired, you can't think. And just a little stimulation might help you expand on what you're experiencing." – surrogate "That would be a great thing for physicians to know, these are things that are important to families." –physician
Engage surrogates in values elicitation	57 (98)	Engage surrogates to improve patient-centered decision making Communicate about values to aid the clinical team in developing a picture of the patient as a person Communicate early to decrease emotional decision making and improve patient-centered decision making Frame the delivery of material designed to elicit values appropriately	"I think even if you're the type of person that you say 'I want them to live no matter what', but then you start to talk about their values, it kind of forces you to look at what they would want." –physician "Get to know what my mother is like, and not look at her like just another patient." –surrogate "I think early communication is key. We have data that shows us that." – physician "How and when values elicitation is delivered is going to be the more important part of the intervention." –physician
Provide information about treatment pathways	56 (97)	Reducing stigma related to life support Provide perspective on the options relative to one another Explain treatment pathways, including time-limited trials Clarify the overlap of treatment options	"They may not have such a negative perception to alternative treatments which may make them more open to thinking about which treatments are best for the patient." -physician "Particularly the concept that you can really try very aggressive measures as a time-limited intervention. That you're not making a permanent decision to commit to that." -physician "The more I do this, the more I try to incorporate to the family that we have the ability to mix treatments." -physician
Present prognostic information	55 (95)	Decrease misunderstandings Clarify that care providers—not surrogates—are responsible for identifying and correcting discrepancies Present post-discharge care needs Report the degree of uncertainty associated with the prognostic estimates	"I think it would be a good idea 'cause the doctor doesn't know what you're thinking, and you don't know what they're thinking, unless you tell them." -surrogate "There's often a disconnect, and we think that we are providing clear information, and it's not always interpreted the way we think we're presenting it." -physician "it's really hard from our perspective to prognosticate and give them some of the information that they really want because we just don't know, and I think that's okay." -physician
Providing psychosocial resources	57 (98)	Decrease stress for surrogates Prompt self-care for surrogates Provide a space for families' expression and reflection Provide the perceptions of other family members by either speaking to one another in real time or watching videos of the experiences others had in the past	"I needed the priest. I really didn't know how to contact him. So I had told the nurse, and that's how I got in contact with him." -surrogate "They advise you to eat regularly and not go without eating." -surrogate "I think anything that you go through, if you can talk to other people that have gone through it, it takes some of the mystery out." -physician

acceptable components of a support tool. They were then asked to provide potential benefits of the domain (Table 1).

The next part of the interview addressed stakeholders' perceptions of the acceptability of the tablet-based, web-enabled medium in general, as well as any design suggestions for such a tool. Interviewees were asked, "Do you think this would be useful to you as a family member with a loved one in the ICU? Why? Why not?"

Interview probes were refined throughout the data collection process in order to explore emerging themes. Enrollment continued until thematic saturation was achieved.

2.6. Analysis

Interviews were audiorecorded and transcribed verbatim. A multidisciplinary team reviewed transcripts, identified emerging themes using the method of qualitative description [50], and incorporated them into a comprehensive codebook. We refined the codebook via an iterative process to develop a final coding framework.

Two coders then applied this framework to the transcripts. All disagreements between coders were reviewed in team meetings and consensus was achieved. Coders had good inter-rater reliability as evidenced by an overall Kappa statistic of 0.89 (NCE, AMS). We used ATLAS.ti software (Berlin, Germany) for qualitative data management.

3. Results

3.1. Participants

Table 2 summarizes the socio-demographic characteristics of the 58 key stakeholders, consisting of 30 surrogate decision makers, 8 ICU physicians, 15 nurses, 3 spiritual care providers, and 2 social workers. The average interview length was 28.9 minutes.

3.2. Interviewee Perceptions

3.2.1. Acceptability: Main Benefits of a Communication and Shared Decision Making Support Tool

Overall, 95% (55/58) of participants perceived that a technology-driven intervention would be acceptable. The main benefits of the tool reported by stakeholders during the interviews were: (1) enhancing and supplementing communication between surrogates and the clinical team, (2) leveraging surrogates' downtime before and between clinician-family meetings, (3) helping surrogates to consider the patient's values and treatment options, and (4) allowing for repetition and review of information. Table 3 contains the main perceived benefits and representative quotes from stakeholders. Three participants (5%) did not think the tool was acceptable, citing that: (1) a full-length video to watch at home is time-consuming and cognitively taxing, (2) participants may be overwhelmed by the technology, and (3) the material being presented may be too emotionally sensitive (Table 3).

3.2.2. Perceived Usefulness: Decision Support Content

Surrogates highly rated the seven content domains presented. Ninety-eight percent (57/58) of interviewees found six or more of the seven content domains acceptable. A presentation of the acceptability of all domains, considerations for each, and exemplars can be found in Table 1. For example, when participants were asked why they found the content domains acceptable, one surrogate said, "Being told about the decision that's going to be made, that's helpful."

3.2.3. Design Suggestions

Participants expressed several suggestions for the tool's conceptualization, design, and integration into the flow of care (Table 4), including: (1) conceptualize the tool as a supplement rather than a substitute for communication with clinical team, (2) allow flexibility with respect to how, when, and where the tool is used, (3) minimize cognitive load

 Table 2

 Participant characteristics. Numbers displayed are count (%) unless stated otherwise

Characteristics	All Participants (N = 58)			
	Surrogates (n = 30)	Physicians (n = 8)	Other Providers (n = 20)	
Age in years, Mean (SD)	48.73 (11.99)	36.63 (3.74)	42.80 (11.48)	
Male	9 (30)	3 (37.5)	4 (20)	
Race				
Caucasian	24 (80)	7 (87.5)	20 (100)	
African American	5 (16.67)	0 (0)	0 (0)	
Asian	0 (0)	1 (12.5)	0 (0)	
Multiethnic	1 (3.33)	0 (0)	0 (0)	
Ethnicity: Hispanic	2 (6.67)	0 (0)	1 (5)	
Education				
Some high school or less	1 (3.33)			
High school diploma/GED	10 (33.33)			
Some college	8 (26.67)			
College degree	5 (16.67)			
Graduate/professional degree	6 (20)			
Have prior experience as a	11 (36.67)			
surrogate decision-maker				
Interviewed during 3-month	4 (13.33)			
follow-up call				
Medical Training Level				
Attending		5 (62.5)		
Fellow		3 (37.5)		
Medical Specialty				
Internal medicine		7 (87.5)		
None		1 (12.5)		
Practice duration in years, Mean		5.96 (3.78)	19.45 (12.32)	
(SD)				
Discipline				
Nursing-bedside			1 (5)	
Nursing-administration			14 (70)	
Social work			2 (10)	
Spiritual care			3 (15)	
Conference Length in minutes (all participants), Mean (SD)	28.9 (9.3)			

by using video and audio in conjunction with a small amounts of text, (4) make the tool interactive, and (5) build an extremely simple user interface to account for individuals with low technology literacy.

A summary of decision support content domains and design suggestions for a communication and shared decision making support tool is provided in Table 5.

4. Discussion

Using in-depth interviews with key stakeholders, we found broad support for the use of a tablet-based, web-enabled communication and decision support tool for surrogates of critically ill patients. Nearly all stakeholders we interviewed responded positively to the preliminary design concept and content, and provided valuable suggestions to further tailor the tool to surrogates' needs in ICUs. Eliciting the perspectives of key stakeholders early in the design process yielded important suggestions—such as using video and interactive features—to create a tool tailored to the mindset of families in ICUs.

The proposed tool is novel in that—rather than being focused on a discrete decision typical of decision aids—it is designed to facilitate communication between the clinical team and the family throughout the course of the ICU stay by providing a series of short videos and interactive features for different stages of the ICU stay. Previous tools have focused on only one task—such as prolonged mechanical ventilation [29] or in non-time-sensitive environments (e.g. advance care planning) [51]. Our approach is an important advance because surrogates in ICUs face many and diverse decisions over time and it would be infeasible to develop a formal decision aid for each discrete decision. Numerous studies have shown that communication near the end-of-life is inadequate, and the proposed tool will be designed to supplement and foster

Table 3Reasons participants (55/58) found a tablet-based tool acceptable and reasons participants (3/58) did not think a tablet-based tool was acceptable

Potential benefits of the communication and shared decision making support tool		Exemplars			
Enhance communication betw surrogates and the clinical to		"I think it's helpful because it gives the physician sort of a starting point too everybody is coming from a different placeI think it would be helpful to have that, at least as a starting point for discussion."			
Leverage surrogates' downtim and between clinician-family meetings		"It seems like it could be more immediate and you can get learning right away. For the four hours we were sitting there and waiting, we could have watched that."			
Direct surrogates to think about the patient's values and treatment options		"So, so letting the, letting the family members kind of, you know, talk among themselves, set themselves up, decide on a time and then, and then get the material and, and then in a, in measured paces, consume the material or expose themselves to it. I think that would be pretty ideal."			
Facilitate repetition of informa	tion	"We could also rewind and watch it again, 'cause we didn't understand something."			
Participants who did not Feedback find the tool acceptable					
Surrogate Nurse Administrator	while me the time tired an "No. Become he a critica	"I don't know, truthfully, if you handed me a video while my husband was in the ICU that I would take the time to look at it. Go home when I'm dead tired and put a video in? No, I don't think so." "No. Because they're not always tech savvy enough do so. There's mostly elderly people that come here. They don't embrace technology, and in a critical time, they're certainly not going to be receptive to something like that."			
Physician "I ei ar Ar ab		to sometime into that, think you should do a video. You want to e with your loved one or you want to sit with your family and support each other, ask a family member to sit down and learn aree different care pathways in the ICU? I 't watch it."			

communication longitudinally over the course of the ICU stay to improve both surrogate well-being and patient-centered care, concepts that were reinforced by stakeholders in this study [6,8].

We found high acceptability of a tablet-based intervention in the ICU environment. This finding is similar to recent studies of technologybased decision support tools in advanced illness. Cox et al. found both high usability scores for an electronic decision aid for prolonged mechanical ventilation and also a strong preference for the electronic version over printed counterparts. [52]. The study was conducted in the high-stress ICU environment, where our tool would also be implemented. Sudore et al. found high ease-of-use ratings among older adults with limited technology literacy for a web-based advance care planning tool [51]. Furthermore, in a systematic review of consumer health information technologies, Or et al. found a majority of studies reporting acceptance of technology across various healthcare domains, including information access and exchange, decision making, social and emotional support, and behavioral change [53]. Our study provides important evidence that a web-based support tool is acceptable to users even with a combination of these factors—age, ICU environment, and longitudinal decision making.

4.1. Strengths

This study has several strengths. First, we included a diverse group of clinician and family stakeholders, including individuals currently engaged in surrogate decision making as well as those who had been

Table 4

Design suggestions for a tablet-based communication and shared decision making support tool

Design suggestions for communication and shared decision making support tool	Exemplars			
Enhance and supplement (rather than replace) communication with clinical team	"The nurse would be able to give them the video when they said, 'OK, we're ready to watch this one now,' then that would be probably more idealized."			
Allow flexibility with respect to how, when, and where the tool is used	With respect to location: "It doesn't even have to be the iPad sitting in front of you in the hospital. Here's the links; it's for you at your disposal or if you want to send an email to your family members and they can look so when they show up, they're prepared." With respect to timing: "So I guess it's the timing. I'm sure you wouldn't talk about that maybe at the beginning of the ICU, but as time went on and decisions have to be made, yes, I think that would be good."			
Use video and audio in conjunction with small amounts of text	"I don't think a lot of people could concentrate on like written documentation 'cause it's easier to hear it, so I guess that would be the best way, would be like a video to hear somebody talking."			
Use interactive features	"Ask a question, hit a topic. Video interactive, I think that would be great."			
Build an extremely simple user interface	"But not everybody's computer savvy, either. So it would have to be very user- friendly."			

through the entire process of surrogate decision making previously in the past. By doing this, we potentially captured real-time desires of surrogates and thoughts of family members after they have had more time to reflect on the ICU stay. Second, methodologically, we interviewed participants to thematic saturation, and we developed a coding framework to capture these themes inductively as they developed, offering a more comprehensive qualitative dataset. The process of eliciting perceptions of stakeholders provided strong support for the perceived value of the tool. The process also revealed that a small number of participants had reservations about the tool. Some of these reservations appeared to be superable with modifications to the user interface, but it is likely that a small subset of surrogates may prefer not to use such a tool; this will be assessed further in the pilot trial of the intervention.

Table 5

Key content domains and design suggestions that will shape the development of a communication and decision support tool

Key Content Domains of Surrogate Support

- 1. Orient surrogates to ICU
- 2. Explain surrogate decision making principles
- 3. Provide question prompt list
- 4. Engage surrogates in values elicitation
- 5. Provide information about treatment pathways
- 6. Present prognostic information
- 7. Providing psychosocial resources

Design Suggestions for Communication and Shared Decision Making Support Tool

- 1. Enhance and supplement (rather than replace) communication with clinical team
- 2. Allow flexibility with respect to how, when, and where the tool is used
- 3. Use video and audio in conjunction with small amounts of text
- 4. Use interactive features
- 5. Build an extremely simple user interface

4.2. Limitations

This study has several limitations. First, our sample is English speaking and predominantly Caucasian, and the study population may not account for low-income and low technology literacy perspectives. Diagnostically, our patient population's primary diagnosis was acute respiratory distress syndrome; concerns might be different for the families of patients with other diagnoses. Physicians' mean years in practice were rather low, as the sample included residents and fellows; more senior perspectives may provide different insight. Although we used both open- and closed-ended strategies to ascertain important content and design suggestions, it is possible that not all important themes arose even in the presence of theoretical thematic saturation. More broadly, participants raised concern that that the tool will be used as a replacement rather than a supplement to actual conversations between clinicians and families. We purposefully designed the tool to minimize this risk by constructing a tool to help families prepare for their conversations by listing their questions, recording their perceptions of the patient's condition, and thinking in advance about the patient's values. The tool does not contain any kind of information about the individual patient, and thus is unlikely to appear to clinicians or surrogates as a viable replacement for conversations. Finally, although broadly acceptable, it is possible that such a tool may be overwhelming to some surrogates. The next step in the project is intensive usability testing, in which we will assess users' responses to the actual tool and make refinements to improve it.

4.3. Conclusions

We found broad preliminary support among stakeholders for the use of a tablet-based tool to improve communication and shared decision making in ICUs. Eliciting the perspectives of key stakeholders early in the design process yielded important insights to create a tool tailored to the needs of surrogates and care providers in ICUs. These data provide evidence of acceptability that support the conduct of a larger evaluation study to assess the clinical effectiveness of the tool on patient, surrogate, and health care utilization outcomes.

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