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Key stakeholders' perceptions of the acceptability and usefulness of a tablet-based tool to improve communication and shared decision making in ICUs☆

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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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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 web-enabled, 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