User-Centered Design in the Development of Patient Decision Aids

Authors : Ariane Plaisance, Holly O. Witteman, Patrick Michel Archambault

Abstract : Upon admission to an intensive care unit (ICU), all patients should discuss their wishes concerning life-sustaining interventions (e.g., cardiopulmonary resuscitation (CPR)). Without such discussions, interventions that prolong life at the cost of decreasing its quality may be used without appropriate guidance from patients. We employed user-centered design to adapt an existing decision aid (DA) about CPR to create a novel wiki-based DA adapted to the context of a single ICU and tailored to individual patient's risk factors. During Phase 1, we conducted three weeks of ethnography of the decision-making context in our ICU to identify clinician and patient needs for a decision aid. During this time, we observed five dyads of intensivists and patients discussing their wishes concerning life-sustaining interventions. We also conducted semi-structured interviews with the attending intensivists in this ICU. During Phase 2, we conducted three rounds of rapid prototyping involving 15 patients and 11 other allied health professionals. We recorded discussions between intensivists and patients and used a standardized observation grid to collect patients' comments and sociodemographic data. We applied content analysis to field notes, verbatim transcripts and the completed observation grids. Each round of observations and rapid prototyping iteratively informed the design of the next prototype. We also used the programming architecture of a wiki platform to embed the GO-FAR prediction rule programming code that we linked to a risk graphics software to better illustrate outcome risks calculated. During Phase I, we identified the need to add a section in our DA concerning invasive mechanical ventilation in addition to CPR because both life-sustaining interventions were often discussed together by physicians. During Phase II, we produced a context-adapted decision aid about CPR and mechanical ventilation that includes a values clarification section, questions about the patient's functional autonomy prior to admission to the ICU and the functional decline that they would judge acceptable upon hospital discharge, risks and benefits of CPR and invasive mechanical ventilation, population-level statistics about CPR, a synthesis section to help patients come to a final decision and an online calculator based on the GO-FAR prediction rule. Even though the three rounds of rapid prototyping led to simplifying the information in our DA, 60% (n= 3/5) of the patients involved in the last cycle still did not understand the purpose of the DA. We also identified gaps in the discussion and documentation of patients' preferences concerning life-sustaining interventions (e.g.,. CPR, invasive mechanical ventilation). The final version of our DA and our online wiki-based GO-FAR risk calculator using the IconArray.com risk graphics software are available online at www.wikidecision.org and are ready to be adapted to other contexts. Our results inform producers of decision aids on the use of wikis and user-centered design to develop DAs that are better adapted to users' needs. Further work is needed on the creation of a video version of our DA. Physicians will also need the training to use our DA and to develop shared decision-making skills about goals of care.

Keywords : ethnography, intensive care units, life-sustaining therapies, user-centered design