Participatory Design and Development of a Patient-centered Toolkit to Engage Hospitalized Patients and Care Partners in their Plan of Care

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Introduction and Background

Acute care hospitals have been long recognized as complex, dynamic, and fast-paced environments characterized by suboptimal communication.[1, 2] Providing tools to support communication, patient activation and engagement can improve patient outcomes and lower healthcare costs.[3] Engaging patients in their recovery plan and providing them with information they need to be informed participants in that plan are key strategies for adverse event and error prevention. The aim of this project is to develop and pilot test a web-based patient centered toolkit (PCTK) prototype to improve access to health information and to engage hospitalized patients and caregivers in the plan of care.

Methods

Individual and group interviews were used to identify plan of care functional and workflow requirements and user interface design enhancements. The types of interviews conducted to engage end users in development and refinement of the PCTK were as follows: 1)Bedside interviews with patients and family (Round 1); 2)Patient/Family Advisory Council group interviews; 3)Professional care team group interviews; 4)Bedside interviews with patients/family (Round 2).

Results

The initial prototype lacked specific tools to allow patients and family to document their personal goals, concerns, problems and preferences for care. It did include a space for patients and family to write questions that they could later share with the care team, but patients and family told us that this was insufficient; they wanted to directly communicate with their care team members. We added the care planning tools and a message board to the next prototype but soon learned from patients, family, and care team members that the user interface was too busy and that it would be difficult for older patients or patients who are not computer savvy to use. We simplified the user interface and the care planning tools in the next version of the prototypes and received positive feedback about patient and family intention to use the toolkit.

In our most recent bedside interviews there was a limited sample of 7 participants. Patients told us that they would use the care planning tools if they were available today and that they thought other patients would use it as well. Patients and family also reaffirmed the value of the additional information available from the PCTK such as pictures and roles of care team members, medications, test results, a discharge checklist, food and diet information and tailored information about their condition and their safety risks.

Discussion/Conclusion

Qualitative methods within a participatory design approach supported the development of a PCTK prototype that will be implemented on intensive care and oncology units to engage patients and professional care team members developing their plan of care during an acute hospitalization.

References

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