

Symptom Monitoring and Reporting System for Pediatric Chronic Illness

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Organization:	Northwestern University
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Summary: Children experience distressing physical symptoms caused by cancer and its treatment, with fatigue being the most prevalent symptom. Efforts to manage cancer-related symptoms in children have not kept pace with advances in cancer treatments. Factors contributing to poor symptom management include delay in reporting symptoms to clinicians, limited time during clinic visits, and logistical and organizational barriers that limit the quality of symptom care.

Using health information technology (IT) to alert patients' parents and providers of significant changes in symptoms is one recommended strategy for improving symptom management. This project intends to do that by extending an existing symptom monitoring and reporting system for adult oncology patients to the pediatric oncology population. Dr. Lai and her team will do so by developing a system known as Symptom Monitoring & Systematic Assessment in Young Survivors, or SyMon-SAYS (formerly SyMon-Peds). SyMon-SAYS is a patient-oriented system intended to provide a mechanism for reporting symptoms experienced by pediatric cancer patients to their parents and health care providers. This study focuses on monitoring only a single symptom; fatigue. By using the SyMon-SAYS system, pediatric oncology patients or their parents can report their fatigue at home between clinic visits using any Internet-accessible device, such as a computer or smartphone, or a regular telephone via interactive voice response (IVR) technology. Using templates developed for fatigue reports and programming SyMon-SAYS, the system will collect and store fatigue symptoms reported by patients and parents and will generate fatigue reports accordingly.

These reports will be transmitted to clinicians, detailing graphic displays of patients' weekly fatigue status and highlighting changes from week to week. Significantly high fatigue scores or increases in fatigue levels will be detected by the SyMon-SAYS system and activate an alert. This alert notifies a clinician to contact the parent of the patient to consult on managing fatigue or to ask the patient to come into the clinic. After developing and pilot-testing the system, a prospective cohort study of 100 patient (ages 7 to 17) and parent dyads will be conducted to evaluate: 1) the feasibility of implementing the SyMon-SAYS system in clinics; 2) patient/parent perceived usefulness; 3) provider satisfaction; and 4) efficacy of the SyMon-SAYS system in managing fatigue in pediatric cancer patients. Participants will complete an 8-week intervention in which they will login to the system weekly, either by telephone or Internet, to report on the perceptions of the patients' fatigue. If patients' fatigue scores reach or exceed a predefined threshold, a study nurse will notify oncologists and contact the patients' parents to provide care

recommendations in real time. The overall goal of the project is for SyMon-SAYS to improve symptom management for pediatric cancer patients.

Specific Aims:

- Evaluate the feasibility of implementing the SyMon-Peds system in a pediatric oncology clinic, its acceptability (defined as perceived usefulness) by parents of children with cancer and the clinicians' and parents' satisfaction with the system. **(Ongoing)**
- Explore the efficacy of the SyMon-Peds in managing fatigue. **(Upcoming)**

2011 Activities: During 2011, the fatigue report templates were created and the SyMon-SAYS system was developed and programmed. The patient and clinician interfaces of the system (i.e., the Web site and the IVR system) were built and quality-assurance tested. Training materials for study personnel (physicians, nurses, and research assistants) at Children's Memorial Hospital were developed, and trainings were conducted in October 2011. The system was modified to incorporate suggestions made by clinicians during the training sessions.

Pilot testing of the SyMon-SAYS system was completed as planned. Five patient-parent dyads were recruited to test the functionality of the system, the data collection and management processes, and the feasibility of the logistics associated with the intervention flow. All five dyads completed the pilot testing. Based on the findings, the research team determined that no changes to the system or process were needed. The five dyads enrolled in the pilot test will continue participation and be counted as participants of the main study. Full implementation of the SyMon-SAYS system and recruitment will continue in 2012.

As last self-reported in the AHRQ Research Reporting System, project progress and activities are mostly on track and project budget funds are somewhat underspent because proposed funds for travel and personnel costs were less than anticipated for 2011. Specifically, the research assistant for this project was unable to dedicate the percentage effort needed to support the full set of tasks and responsibilities required by the project. In 2012, the research assistant's percentage effort for this project will be increased to better support the needs of this project, thereby spending down remaining funds from 2011.

Preliminary Impact and Findings: This project has no findings to date.

Target Population: Cancer, Pediatric*

Strategic Goal: Develop and disseminate health IT evidence and evidence-based tools to improve health care decisionmaking through the use of integrated data and knowledge management.

Business Goal: Implementation and Use

* This target population is one of AHRQ's priority populations.