

Symptom Monitoring and Reporting System for Pediatric Chronic Illness

Principal Investigator:	Lai, Jin-Sheri, Ph.D., OTR/L.
Organization:	Northwestern University
Mechanism:	PAR: HS08-269: Exploratory and Developmental Grant to Improve Health Care Quality Through Health Information Technology (IT) (R21)
Grant Number:	R21 HS 019071
Project Period:	March 2011 – February 2014
AHRQ Funding Amount:	\$297,787

Summary: Children experience distressing physical symptoms, most prevalently fatigue, from cancer and its treatment. 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 to significant changes in symptoms is one recommended strategy for improving symptom management. Building on an existing symptom monitoring and reporting system for adult oncology, Dr. Lai and her team have developed Symptom Monitoring & Systematic Assessment in Young Survivors, or SyMon-SAYS (formerly SyMon-Peds). SyMon-SAYS is a patient and parent-oriented system intended to provide a mechanism for reporting symptoms experienced by pediatric cancer patients to their health care providers. This study focuses on monitoring only a single symptom, fatigue, due to the feasibility nature of this study. By using SyMon-SAYS, pediatric oncology patients or their parents can use any Internet-accessible device, such as a computer or smartphone, or a regular telephone via interactive voice response technology to report fatigue occurring between clinic visits. Using templates developed for fatigue reports in SyMon-SAYS, the system collects and stores reported fatigue symptoms and generates fatigue reports accordingly.

These reports are 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 are detected by the SyMon-SAYS system and activates an alert to the clinician. Upon developing and pilot-testing the system in the first year of the project, Dr. Lai and her team initiated a prospective cohort study of 50 patient (including children ages 7 to 17 and young adults ages 18 to 30) and parent dyads to evaluate: 1) the feasibility of implementing the SyMon-SAYS system in clinics, 2) patient and parent perceived usefulness, 3) provider satisfaction, and 4) efficacy of the SyMon-SAYS system in managing fatigue in pediatric cancer patients. During the study, participants complete an 8-week intervention in which they log into the system weekly, either by telephone or Internet, to report perceptions of the patients' fatigue. If patients' fatigue scores reach or exceed a predefined threshold, a study nurse notifies an oncologist. If the patients' fatigue is unexpected, clinicians contact the patients' parents to provide care recommendations in real time.

Specific Aims:

- Evaluate the feasibility of implementing the SyMon-SAYS (formerly 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-SAYS (formerly SyMon-Peds) in managing fatigue. **(Upcoming)**

2012 Activities: The project team implemented the SyMon-SAYS system and enrolled participants in the feasibility study. Dr. Lai had planned for the feasibility study to include 100 patient-parent dyads (including patients 7 to 17 years of age), but enrollment was slower than anticipated. To address this, Dr. Lai first added an additional oncology clinic in Chicago to the study in an effort to increase patient enrollment. As recruitment and enrollment continued to lag during 2012, Dr. Lai modified the eligibility criteria to include young adult patients (18 to 30 years of age) in the study. While these efforts increased enrollment, Dr. Lai eventually modified the recruitment goal to 50 upon determining that it would not be feasible to recruit 100 participants in the study in a timely manner. By the end of 2012, the team had met their new recruitment goal of 50 participants and planned to continue recruiting for the study through January 2013 in an effort to enroll additional participants to account for potential attrition.

To better understand the barriers to recruiting participants into the SyMon-SAYS feasibility study as well as how using the system impacts clinician workflow and work load, Dr. Lai conducted formal interviews with six clinicians (two doctors and four nurses). Dr. Lai found the information gained from these interviews to be helpful in understanding how the system could be modified to better meet clinicians' needs and be better integrated in clinical workflow if it implemented on a wider scale. For example, clinicians felt they already monitored patients' fatigue closely and there is no need to have patients report their fatigue weekly. However, they still feel the report is helpful and are willing to receive patients' fatigue reports regularly, with a preference of monthly rather than weekly for patients who do not generate a fatigue alert.

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 personnel costs were less than anticipated for the first 2 years of the project. Dr. Lai is using a 1-year no-cost extension to allow additional time for analyzing and disseminating the feasibility study findings.

Preliminary Impact and Findings: Qualitative research findings indicate both patient and parent participants as well as clinicians have positive impressions of the SyMon-SAYS system, finding it to be easy to use and helpful in managing fatigue. The final results from this study will be analyzed and reported on during the third year of the project.

Target Population: Cancer, Pediatric*, Teenagers

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.*