

Improving Pediatric Cancer Survivorship Care through SurvivorLink

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Organization:	Emory University
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Summary Status as of:	December 2010

Target Population: Cancer, Pediatric*

Summary: As the numbers of survivors increase, cancer survivorship has become a national public health priority. This is particularly true for childhood cancer survivors for whom cancer therapies, with overall cure rates of 75-to-80 percent, are highly successful. Yet high-quality, individualized survivorship care is challenging due to: 1) multiple transitions in care among primary and specialty care providers, and 2) the lack of knowledge about survivor issues among providers, patients, and their families.

This project aims to address these challenges by building the SurvivorLink system, a personal health record that will improve pediatric cancer survivors' transition to primary and specialty care for pediatric and increase patient, family, and provider knowledge about survivor issues. SurvivorLink will include a cancer treatment summary, individualized risk- and late-effects screening profiles, and other clinical information needed to provide high-quality long-term care to survivors. In addition, there will be educational materials that improve awareness of survivorship issues and best practices in survivor care.

SurvivorLink has three target user groups: patients and families; providers; and researchers. For this pilot study, patient, family, and provider participants will be recruited through the five cancer treatment centers in the State of Georgia and through Georgia Comprehensive Cancer Registry records. The impact of SurvivorLink will be evaluated by measuring outcomes related to both SurvivorLink utilization and the effects that SurvivorLink utilization has on aspects of survivor care, including patient and provider awareness of survivor issues and percentage of patients receiving recommended survivorship care.

Specific Aims:

- Collect data on pediatric cancer survivors in SurvivorLink. **(Ongoing)**
- Facilitate the exchange of clinical information at key transitions. **(Ongoing)**
- Provide patients with easy access to individualized educational materials and evidence-based late-effects screening recommendations. **(Ongoing)**
- Provide researchers with longitudinal information on incidence of late effects in pediatric cancer survivors. **(Upcoming)**

2010 Activities: The project team conducted focus groups and semi-structured interviews with providers, patients, and parents to understand the needs of these groups. The focus groups indicated that providers want a system that allows efficient access to patient health information before the patient visit. Patients and their parents expressed concern about privacy from insurance companies, colleges, and employers. As a result, the patient-parent portal was designed with special attention to security and privacy. Similar to a social networking site, patients and parents can invite their primary care doctor and other physicians to access their survivor health plan online to facilitate information exchange, and can un-invite them at any time. When patients or parents sign up, they receive a survivor health care plan and give permission for their providers to post information. The portal highlights tailored information for individual patients based on their risks. Patients and parents are also able to link their current medications with relevant health links and to store other information as scanable documents. As an added security measure, patient and parents are able to monitor who looks at their patient information.

Dr. Mertens held several seminars to educate providers, including pediatricians, social workers, oncologists, and endocrinologists about SurvivorLink. Additionally, all pediatricians in the State were notified of the system. To date, 55 providers have registered. In September 2010, patient and parent recruitment was initiated at the largest clinic via mailings and followup phone calls. A total of 26 users have registered (19 parents and 7 patients) toward the recruitment goal of 500. In 2011, patient and parent recruitment will begin at the other clinics. Dr. Mertens will also recruit patients and parents from community-based pediatric cancer support groups.

Grantee's Most Recent Self-Reported Quarterly Status (as of December 2010): The project is meeting most milestones on time. Project spending is roughly on target.

Preliminary Impact and Findings: Findings from focus groups with providers and parents of pediatric cancer survivors were incorporated into the development of the parent-patient portal of SurvivorLink. During followup recruitment phone conversations, the project staff learned that most parents were not familiar with the importance of survivor care.

Strategic Goal: Develop and disseminate health IT evidence and evidence-based tools to support patient-centered care, the coordination of care across transitions, and the electronic exchange of health information to improve quality of care.

Business Goal: Implementation and Use

* *AHRQ Priority Population*