Improving Pediatric Cancer Survivorship Care through SurvivorLink

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Abstract

Purpose: The over-arching aim of this project is to build SurvivorLink, an IT system designed to support pediatric cancer survivor care by increasing knowledge of the importance of survivor care, and promoting communication between providers and parents/patients through use of an electronic personal health record maintained by the patient and shared with their provider.

Scope: Due to improvements in cancer therapy over the past three decades, children diagnosed with cancer are living longer. Childhood cancer and its subsequent treatment predispose survivors to a higher risk of certain life-threatening and debilitating diseases called late effects of cancer treatment. With the growing number of survivors and the increasing awareness of late effects, cancer survivorship has become a national public health priority.

Methods: Assessment of the needs of health care providers and parents/young adult survivors was conducted using a mixed methods research design. Data was collected to develop a more complete understanding of the issues around needs and use of a tool to improve awareness and knowledge of survivor care. Data collection for the evaluation of SurvivorLink consisted of: 1) structured interviews with health care providers; focus groups with parents and young adult cancer survivors, 2) SurvivorLink system data and logs, and 3) participant surveys.

Results: Results from these strategies suggest that familiarity with the importance of cancer survivorship is poor among both survivor/parents and healthcare providers. Education improved registration and use of the website. Results also demonstrated the importance of refining education and recruitment strategies within both survivors and their parents.

Key Words: pediatric cancer; survivorship; personal health record; information technology

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Final Report

Purpose

The over-arching aim of this project is to build SurvivorLink, an IT system designed to support pediatric cancer survivor care, by increasing knowledge of late effects and the importance of survivor care, and promoting communication between providers and parents/patients through use of an electronic personal health record maintained by the patient and shared with their provider.

In the original grant application, we stated we will apply IT system development best-practices to design and develop the core components of SurvivorLink. The system objectives are to:

- Collect clinical data on pediatric cancer survivors in an electronic health record. This record may be shared by patients with any providers involved in their care to improve communication and provide better data to support clinical decisions in the life-long care of these patients.

- Facilitate the exchange of clinical information at key care transitions which include the transition from cancer treatment by the oncologist to long-term survivor care by other provider(s); transitions in care providers due to relocation, job change, or insurance change; and the transition from the pediatric care system to the adult care system at age 18-21.

- Provide patients easy access to individualized educational materials and evidence-based late-effects screening recommendations, enabling them to take a more active role in their care.

- Provide primary care and specialty care providers with evidence-based recommendations and other education materials related to quality survivor care and with easy access to information on their patient’s cancer treatment, individualized risk profile and information on any chronic conditions and late effects experienced by the patient following cancer treatment.

- Provide researchers with access to more complete longitudinal information on incidence of late effects in pediatric cancer survivors, enabling them to conduct innovative research to add to the evidence base on late effects prevalence and prevention.

SurvivorLink was implemented using a phased approach and piloted with pediatric cancer survivors treated in Georgia, and primary and specialty care providers in Georgia who care for these patients once their cancer is cured. This created patient-centered tool enables patients to share with their provider their individualized, evidence-based information about late effects they are at risk for and which surveillance tests are recommended for detection of these late effects.
Scope

Background

Due to improvements in cancer therapy over the past three decades, children diagnosed with cancer are living longer. Data from the National Cancer Institute shows that the overall 5-year survival rate for childhood cancer has increased from 45% in 1970 to over 80% in 2007. Because of these high survival rates, it is estimated that the number of years of life saved in these children is second only to breast cancer patients, the most common cancer in women in the US. Approximately 328,000 adults are childhood cancer survivors; this translates into one in every 640 young adults (age 20-34).

Childhood cancer and its subsequent treatment predispose survivors to a higher risk of certain life-threatening and debilitating diseases called late effects of cancer treatment. Numerous reports and reviews of late effects of chemotherapy and radiation have described the sequelae that may present at the end of therapy, shortly following the end of therapy, or years after the completion of therapy. These studies have shown that type and intensity of therapy, as well as the age at therapy, are important factors in both overall survival as well as late effects risks. Children who are younger at diagnosis and treatment are more severely affected than older children, particularly if treatment is administered at a significant time of development and growth.

Context, Settings

With the growing number of survivors and the increasing awareness of late effects, cancer survivorship has become a national public health priority. The Institute of Medicine (IOM) report Childhood Cancer Survivorship: Improving Care and Quality of Life in 2003 proposes a comprehensive policy agenda that links improved health care delivery, investments in education and training, and the need for a plan to transition these children back to the primary health care setting. This report and others emphasize the need to raise awareness about issues surrounding life after cancer—not just among survivors, but also among care providers, policy makers, family members, friends and the public. The IOM also published two seminal reports on survivorship: From Cancer Patient to Cancer Survivor: Lost in Transition (2006) which addresses the unmet needs of adult survivors following primary treatment; and Implementing Cancer Survivorship Care Planning (2007) which assesses the implementation of survivorship care planning. These reports confirm that patients, caregivers, and healthcare providers need the knowledge and tools to ensure that patients get the best possible care during the survivor phase of their cancer care.

A number of barriers to survivor care have been identified for pediatric cancer survivors, including: survivor lack of knowledge about late effects and individualized risk for specific late effects; and lack of availability of or knowledge about appropriate cancer survivor follow-up programs, leading to survivors not receiving recommended care per COG guidelines. In a survey of adult survivors of pediatric cancer, 88.8% of the survivors reported having received health care in the previous 2 years but only 31.5% reported survivor-focused care and only 17.8% reported receiving risk based care recommended by the COG LTFU Guidelines. When asked about information regarding their previous cancer diagnosis, only 22% stated they had a treatment summary or copies of their medical records of their childhood cancer, and only 31%
thought that their primary care doctor had a summary of their treatment for childhood cancer. Additional barriers to comprehensive longitudinal survivor care include: transition between providers, geographic mobility, cost of travel to an oncology center, and lack of awareness of the need for life-long risk based care. To ensure survivors receive optimal long-term follow-up care, shared models of care that include PCPs should be considered and tailored to the survivors needs.

**Participant, Incidence, Prevalence**

The diverse make-up of Georgia provides an opportunity to examine SurvivorLink’s impact across various populations. In 2010, Georgia had a population of 9,686,653. In this population, approximately 26% are under the age of 18; 51.2% are female. It is estimated that this population is approximately 59.7% white, 30.5% black, 3.2% Asian, and 6.6% other race. 8.8% of this population is persons of Hispanic or Latino origin. According to the U.S Census Bureau, 75.07% of the population resides in an urban area, 24.93% are rural. Within Georgia, it is estimated that 21.5% of children under 18 are living below the poverty level. For children under the age of 18 in Georgia, 31% are covered by Medicaid, and 12% children have no insurance coverage. This demonstrates the diversity of the population, and the opportunity to leverage this study with a designated priority population.

According to the Georgia Comprehensive Cancer Registry, the age-adjusted childhood (ages 0 to 19) cancer incidence rate is 150 per 1,000,000; averaging 398 new cases in Georgia per year. From national data, we can extrapolate that there are currently over 10,000 pediatric cancer survivors in Georgia.

**Methods**

**Study Design, Data Sources/Collection**

Assessment of the needs of health care providers and parents/young adult survivors was conducted using a mixed methods research design to develop a more complete understanding of the issues around needs and use of the SurvivorLink website as a tool to improve awareness and knowledge of survivor care, and to promote self-care and adherence to follow-up care recommendations. Data collection for the evaluation of SurvivorLink consisted of: 1) structured interviews with health care providers; focus groups with parents and young adult cancer survivors, 2) SurvivorLink system data and logs (website), and 3) participant surveys (pre-test / post-test design).

**Interventions**

For the purposes of the proposed research population, we recruited pediatric cancer survivors two years or more off treatment that live in Georgia, utilizing records from the five pediatric cancer centers in Georgia, as well as the Georgia Comprehensive Cancer Registry (GCCR). Patients/parents were recruited to participate in the SurvivorLink pilot, and participants utilized the pilot SurvivorLink system and provided feedback on it.
Eligible participants were children diagnosed with cancer between ages of 0-18, diagnosed between 1995-2004, off cancer therapy for at least 2 years, and under the age of 21 at the time of contact. (Note: participants were survivors who are 18 yrs or older or a parent if the survivor was less than 18 at contact). Based on data from GCCR, we estimated that there were 1500 childhood cancer survivors who are eligible for this study. We estimate that approximately 70% of these patients have been seen at one of the participating Georgia pediatric cancer centers. Because of the time and resource constraints of this grant, we randomly selected a sub-sample of cancer survivors to be recruited for this study. For the proposed research we targeted to recruit:

- Survivors who were treated at one of the 5 Georgia pediatric cancer centers and not followed in a pediatric cancer survivor programs;
- Survivors who will be identified through the GCCR who were not treated at one of the 5 Georgia pediatric cancer centers and have not been seen in a pediatric cancer survivor program;
- Survivors who have been seen at the Aflac Cancer Survivor Program and already have their survivor healthcare plan (SHP).

Eligible survivors/parents for this project received a letter from the medical director of SurvivorLink inviting them to participate in SurvivorLink. The recruitment mailing included an introduction to SurvivorLink, an invitation to register on the SurvivorLink website, and a consent form informing parents/patients that they will be asked to complete a baseline and follow-up surveys. Signed consent forms were returned to the Department of Pediatrics at Emory University, in a stamped addressed envelope (included with the introductory packet). If the signed consent forms were not received within three weeks of the original request, a follow-up telephone call was made to the survivor/parent by a trained telephone interviewer, to discuss the study with them, give them an opportunity to ask questions, and encourage them to return the consent form and register on SurvivorLink.

If participants do not have Internet access in their home, they were also given instructions on community based venues to access the internet such as the school system or the Georgia Public Library System, and were given the option of receiving all educational material that is available on SurvivorLink in print format.

**Measures**

**Qualitative data** was obtained at the early stage of the grant, by collecting data on current challenges in survivor care especially around care transitions, and specific wants/needs of each user group related to survivor care education and quality care delivery. This baseline data on needs was collected through a series of phone interviews with a sample of providers that included oncologists, primary care, and specialty care providers throughout Georgia. In addition, three survivor/parent focus groups were conducted; participants were recruited from two of the five pediatric cancer centers in Georgia, and the patient support group CURE, and Camp Sunshine, a community based resource for children diagnosed with cancer and their families. **Surveys** were conducted to collect study data from participants at various points in the study. Participating parents/patients and providers were surveyed at this time of registration on
SurvivorLink, which served as the baseline data. A follow-up survey was administered 12 months after registration on SurvivorLink.

**System utilization data** are being collected real-time through the SurvivorLink system. User registration details are logged at the point of registration. Other utilization data is captured in web logs and analyzed using standard website reporting tools. Data viewed audit trails built into SurvivorLink for privacy purposes provide data needed to report metrics on page-level views by user.

**Limitations**

Previous research in pediatric cancer survivorship is limited to convenience samples, and of questionable representativeness of the true pediatric cancer survivor experience. To overcome this obstacle, we proposed this project as a population-based initiative for all pediatric cancer survivors in a geographical region—the state of Georgia. Analysis is underway on best methods to better reach remote patients and encourage them to take action on improving their health and overall quality of life.

Another challenge we faced was to find patients lost to follow up since the completion of cancer treatment. We used several resources to minimize this challenge. First, on an annual basis the GCCR cross-references all cancer cases with the Georgia Death Registry, and attempts to contact those still alive to update addresses. Second, we utilized tracing methods that were successful in tracking lost to follow-up patients in a larger cohort of pediatric cancer survivors.

**Results**

**Principal Findings**

SurvivorLink™ (www.cancersurvivorlink.org) was developed as a patient-controlled web-based communication tool to enable survivors to learn about the late effects they are at risk for, store their survivor healthcare plan (SHP) and other important health documents, and share their SHP and other health documents with their various healthcare providers. The objectives for SurvivorLink are to 1) increase awareness of best practices in survivor care for survivors of pediatric and adolescent cancers, 2) provide tools to providers, parents, and patients to facilitate providing high quality care to these patients, and 3) develop a longitudinal health record for these patients that can be used both for care delivery and research to improve survivor care. In practice, SurvivorLink serves as an electronic personal health record (ePHR) for pediatric cancer survivors. ePHRs are an individual’s electronic record of lifelong health-related information that is managed and controlled by the individual who can share appropriate parts with those who need it. Additionally, SurvivorLink provides educational materials to improve awareness of survivorship issues and best practices in survivor care for the survivor/parent and healthcare providers. The primary components of SurvivorLink are described below:

**Patient Portal.** This portal is designed for survivors and parents. It provides educational material targeted to survivors and parents and information about how to find the nearest survivor
Registered participants receive quarterly e-newsletters highlighting certain aspects of survivor care. Survivors (or parents) who have registered with SurvivorLink can store their SHP, and other important health documents. Patients can upload any Microsoft Word, PDF, scanned image, or text file, including summary letters from specialist, important lab or imaging test results. Survivors/parents can share this information with any healthcare provider they choose using SurvivorLink’s security and privacy controls. For each survivor, an access log is automatically provided that displays who has viewed the survivor’s uploaded documents. If the survivor had their SHP developed at a partner clinic and a medical records release is signed, the clinic can upload a patient’s SHP, which will include summaries of surveillance tests done at the clinic visit.

**Healthcare Provider Portal.** This portal targets healthcare providers. Registered healthcare providers whom patients have selected can view the survivor’s clinical information. Providers can upload documents for their survivors, if the survivor has granted them permission to do so. The healthcare provider portal also provides education materials. These materials were developed based on feedback received during structured physician interviews and educational lectures. Specifically, 19 ‘Quick Fact’ executive summaries’ on organ specific late effects, and six more detailed continuing education (CE) modules in text and video format are available (QuickFact example, appendix 5). More than 90 continuing medical education (CME) credits have been earned via the CE modules available on SurvivorLink. Providers have been enthusiastic about the availability of CME credits for SurvivorLink modules.

**Clinic Portal.** The clinic portal is an administrative interface for clinic personnel to manage clinical information for their patients who use SurvivorLink, and is available to partner clinics. Clinics with this portal access can approve medical record releases, upload clinical information (including a SHP) to the SurvivorLink is designed to enable interfacing with electronic health record (EHR) systems in the future. As health information exchange capabilities are more widely adopted among providers, we intended to provide more automated sharing of information from providers and clinics via their EHR.

**Data Exchange Pilot.** To pilot health information exchange capabilities, an interface between the Aflac Cancer and Blood Disorders Center survivor clinic database and SurvivorLink was developed. This interface electronically transfers SHP information as structured data from the clinic database to the SurvivorLink database for cancer survivor patients who are SurvivorLink users.

**Advisory Board.** The SurvivorLink Advisory Board was established to provide oversight and establish priorities for on-going enhancements and research. The Board includes representatives from each of the five pediatric cancer centers in Georgia, CURE Childhood Cancer (a patient advocacy group), representatives from partner healthcare professional organizations, and the Georgia Cancer Coalition. This Board continues to meet on a regular basis to provide feedback on the website.

**Privacy/Security Protections.** Because SurvivorLink contains sensitive health information, significant time and effort has focused on providing privacy and security protection. Privacy policies have been instituted based on emerging privacy and security principles for electronic
health information exchange and institutional review board (IRB) policies. HIPAA and IRB requirements regarding protection of personal health information (PHI) are met, including providing an audit trail available to survivors/parents of individuals who have accessed the survivor’s health information. All patients have an opportunity to opt in to having their data used for research. Additionally, features have been developed to address the survivor’s transition when they are of age (usually at age 18) from parent control over their health information to the survivor’s control over their health information.

Outcomes

Provider Interviews. To direct the design of the SurvivorLink provider portal, three strategies were undertaken. First, investigators met with pediatric oncology teams from the five Georgia pediatric cancer survivor programs to assess current survivor programs. Second, we completed 11 interviews with Georgia-based health care providers (HCPs) to discuss current challenges in survivor care. Third, to demonstrate SurvivorLink in-person lectures were performed throughout the state of Georgia. For each strategy, HCPs were also invited to visit SurvivorLink and register on the site. Results from the interviews demonstrated:

- All HCPs reported moderate to very low familiarity with late effects management in pediatric cancer survivors.
- Overall, HCPs expressed a high level of interest in SurvivorLink,
- HCP requested survivor healthcare info be presented as quick fact sheets for easy access in a clinical setting

Focus Groups. The current area of development, the patient/family portal, was designed with input from focus groups with two key users: parents of pediatric cancer survivors, and young adult survivors of pediatric cancer. Summary of Findings from the focus groups are:

- Parents and young adult survivors of childhood cancer have similar needs for educational material on survivor healthcare for both personal use and for their health care providers.
- Both young adults and parents expressed concerns regarding transition of care at crucial time points, and welcomed tools/resources to help with this transition.
- Parents expressed more concerns about the privacy and security of storing personal health information on-line, than young adults.

Recruitment. The recruitment of survivors/parents to inform them of SurvivorLink in this initial AHRQ grant focused on standard mailings, and is shown in the figure below.
In addition, 213 survivors from the Children’s Healthcare of Atlanta (CHOA) tumor registry were contacted via direct mail, stratified on whether they had attended a survivor clinic. This and two subsequent recruitment strategies have been piloted to date (see Table 1). Outreach through community partners was piloted, with SurvivorLink team members attending four events sponsored by community groups invested in pediatric cancer families and patients. In addition, clinic recruitment where SurvivorLink was presented to patients during their visit to the Aflac Cancer Survivor Program (CSP) at CHOA was piloted for a six month period (February 21, 2012 to August 2, 2012). During this time SurvivorLink was presented to 197 patients.

Table 1. Summary of SurvivorLink registration by recruitment strategy

<table>
<thead>
<tr>
<th>Recruitment strategy: standard mailing (n=213)</th>
<th>YA Survivors (N)</th>
<th>YA Survivors Registered (%)</th>
<th>Parents (N)</th>
<th>Parents Registered (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Previously seen in survivor clinic</td>
<td>14</td>
<td>35.7%</td>
<td>54</td>
<td>50.0%</td>
</tr>
<tr>
<td>Never seen in survivor clinic</td>
<td>26</td>
<td>23.1%</td>
<td>119</td>
<td>32.8%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Recruitment strategy: community events (n=70)</th>
<th>YA Survivors (N)</th>
<th>YA Survivors Registered (%)</th>
<th>Parents (N)</th>
<th>Parents Registered (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Families engaged</td>
<td>--</td>
<td>--</td>
<td>70</td>
<td>21%</td>
</tr>
</tbody>
</table>
Table 1c. Recruitment strategy: clinic (n=197)

<table>
<thead>
<tr>
<th></th>
<th>YA Survivors Approached (N)</th>
<th>YA Survivors Registered (%)</th>
<th>Parents Approached (N)</th>
<th>Parents Registered (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Already registered</td>
<td>3</td>
<td>100%</td>
<td>21</td>
<td>100%</td>
</tr>
<tr>
<td>Discussed, enrollment began in clinic</td>
<td>24</td>
<td>62.5%</td>
<td>61</td>
<td>55.7%</td>
</tr>
<tr>
<td>Discussed, received handouts</td>
<td>27</td>
<td>14.8%</td>
<td>46</td>
<td>17.4%</td>
</tr>
<tr>
<td>Not interested</td>
<td>2</td>
<td>0.0%</td>
<td>12</td>
<td>0.0%</td>
</tr>
<tr>
<td>No internet at home</td>
<td>0</td>
<td>--</td>
<td>1</td>
<td>0.0%</td>
</tr>
</tbody>
</table>

Registration and Website Utilization. In the past year, we have had 1,408 unique visitors to the website, and the number of visitors has been steadily increasing. While our recruitment efforts have been focused on the state of Georgia, as that is where our clinic and patient population resides, we have had visitors from 48 states and 42 countries (see map below). We currently have over 550 registered users including 252 parents, 108 patients, 185 healthcare providers, and 10 other.

Figure 2. Geographic location of visitors to SurvivorLink in the United States

Using Google Analytics, we can also track specific utilization of the website. Below are two examples, tracking over a two year period:
Figure 3. Most visited pages in SurvivorLink

Most visited pages in SurvivorLink
(Oct 2009 - Sep 2011)

Figure 4. Survivor utilization vs. outreach events

Survivorlink Utilization vs. Outreach Events (Sep 2010-2011)

Highlight Events:
(1) Mar 17: SL note in CURE newsletter
(2) May 1: CURE Lauren’s Run,
May 3: CHOA press release
(3) Jun 14, 16, 17: Talks at UMN, GCC and AFP
(4) Jun 26: Camp Sunshine sign-ups

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Discussion, Conclusions

The proposed research aims to use health IT to support pediatric cancer survivor care by increasing knowledge of late effects and the importance of survivor care, and promoting communication between providers and parents/patients through use of an electronic personal health record maintained by the patient and shared with their provider. Results from these strategies suggest that familiarity with the importance of cancer survivorship improves registration of the website, and parents are more likely than young adult survivors to use this site. It also demonstrates the importance of refining recruitment strategies within both survivors and their parents.

Barriers to adherence in this at risk population include lack of awareness, poor communication, and provider gaps in knowledge about survivor treatment, risk profile, and evidence-based follow-up recommendations. Through this online portal that provides education tools and shared health records, we will continue to track the effectiveness of this technology to help remove these barriers and achieve improvements in adherence.

The education efforts in this website aim to increase awareness in the primary care setting of the need for long term survivor care. It also provides the knowledge providers need to effectively care for these pediatric cancer survivors many of whom have complex health care needs. We will continue to track the effectiveness of SurvivorLink on its influence to improve adherence to the surveillance plan from the survivor’s SHP.

In addition, the SHP will serve as the foundation for a longitudinal health record for survivors of pediatric cancers. This population-based longitudinal record will enable future research on late effects and transition of care to inform continued enhancements to long term follow-up guidelines for this population.

Significance, Implications

Awareness regarding the need for life-long focused medical care is a significant challenge in both pediatric cancer survivors and their health care providers. Cancer reports from National Cancer Institute, the Centers for Disease Control and Prevention, and the Institute of Medicine in the past 5 years clearly demonstrate the need to set survivorship issues as a priority. The development of appropriate surveillance tools like a survivor healthcare plan (SHP), the availability of that tool for healthcare providers and patients, and a mechanism to track the development and progression of late effects is essential to continued progress in pediatric cancer survivor care.

This website provides the opportunity for an enduring sustainable infrastructure for on-going dissemination of evidence-based cancer survivor health information tailored to the pediatric cancer survivor and their health care provider. For our next steps we will utilize our current collaborations, IT expertise, and relationships with professional groups to reach primary care providers. A second critical component will focus on expanding use of SurvivorLink to all pediatric cancer survivors across Georgia. To accomplish this, we will work with the five pediatric cancer centers in Georgia, patient advocacy groups, and provider organizations across the state to promote use of the system statewide. Additionally, Dr Mertens and Dr Meacham will leverage their existing relationships with the Children’s Oncology Group (COG) and other COG cancer centers across the country to determine how SurvivorLink use can be effectively offered to pediatric cancer survivors nationally.
In the long term, this website will enable measurement of adherence to recommendations in the surveillance plan as clinical data is continuously added to the patient’s ePHR. The longitudinal health record will promote better care through tracking adherence to the recommendations and provides a database that can be used to conduct future comparative effectiveness research.

These efforts will be undertaken through a sustainability plan endorsed by the Division of Hematology/Oncology at Children’s Healthcare of Atlanta/Emory University. We have also received funds through CURE, a patient advocacy group in Georgia to continue feasibility studies aimed to determine effective methods to educate pediatric cancer survivors and their parents about the importance of survivorship care through consumer engagement. These efforts will also focus on young adult survivors of pediatric cancer, and will ascertain information on higher education goals, employment and independent living, with partnership with University Health Centers as models of transition for survivors of childhood cancer. We will also continue to request grant support through the AHRQ mechanism and the PCORI initiative. A primary focus will be to enhance the dissemination of evidence-based health information tools to pediatric cancer survivors and primary care providers that are providing care to populations and communities not reached by our current research efforts.

List of Publications and Products

Published Works


Abstracts


Mertens AC, Meacham L, Cherven B, Edwards P. Facilitating Pediatric Cancer Survivorship Care among Health Care Professionals through SurvivorLink. AHRQ Annual Health IT Grantee and Contractor meeting, poster presentation, 2010.


Electronic Resources: Primary SurvivorLink Web site
www.cancersurvivorlink.org

Electronic Resources: Continuing Medical Education Modules in SurvivorLink


