

The Current Status of Follow-Up Services for Childhood Cancer Survivors, Are We Meeting Goals and Expectations: A Report From the Consortium for New England Childhood Cancer Survivors

Lisa B. Kenney, MD,^{1*} Heather Bradeen, MD,² Nina S. Kadan-Lottick, MD,³ Lisa Diller, MD,¹ Alan Homans, MD,² and Cindy L. Schwartz, MD⁴

Background. National guidelines for follow-up care of childhood cancer survivors have been established. It has not been determined if pediatric oncology programs have successfully incorporated these standards for long term survivor care into clinical practice. **Methods.** To describe survivor services available in a geographically and socio-economically diverse region of the US we surveyed all 12 academic institutions with pediatric oncology programs in the New England (NE) region. **Results.** Participating sites diagnose a median of 34 (range 10–250) new pediatric cancers annually. The 12 institutions have 11 survivor clinics. Clinics are staffed by: pediatric oncologists (11/11); nurse practitioners (7/11); social workers/psychologists (9/11); RNs (5/11); primary care physicians (3/11); and sub-specialists (3/11). Most clinics recommend annual follow-up for all survivors (7/11); however, point of entry into survivor programs is variable.

Treatment summaries and care plans are part of survivor care at each program. Almost all (10/11) refer to sub-specialists to manage late effects. Only 4 programs identified a policy for transitioning survivors to adult care (2 to adult survivor programs, 2 to adult primary-care) and 4 reported this as a problem. Two clinics had no designated funding for survivor services; 8/11 receive institutional support; 5/11 philanthropic. Five institutions conduct research in survivorship (1 government-funded, 2 philanthropy-funded, and 2 both). **Conclusions.** Pediatric oncology services in the NE region are making progress toward meeting follow-up care goals for childhood cancer survivors. Funding for resource intense programs, transitioning care to adult clinical services, volume of sub-specialty referral, and participation in research are common challenges. *Pediatr Blood Cancer* 2011;57: 1062–1066. © 2011 Wiley-Liss, Inc.

Key words: childhood cancer; follow-up care; regional collaboration; survivorship

INTRODUCTION

More than 80% of children and adolescents diagnosed with cancer will become long-term survivors [1], and an estimated 60% of survivors will develop chronic treatment-related health conditions years or decades after completing therapy [2]. Treatment-associated conditions such as second cancers, endocrinopathies, cardio-pulmonary disease, infertility, and learning disabilities can cause severe morbidity, often resulting in early mortality and diminished quality of life for survivors [3–12]. Because of this high incidence of treatment associated morbidity, consensus among pediatric oncologists is that this vulnerable population receive ongoing specialized medical follow-up [13–15].

Comprehensive survivor programs have been developed at cancer centers across the United States to provide long term follow-up care to childhood cancer survivors [16] and pediatric organizations including the American Academy of Pediatrics and the Children's Oncology Group (COG) advocate for specialized risk based care [13]. In 2003, the Institute of Medicine published a report of childhood cancer survivorship that included recommendations for the ideal components of follow-up care systems [17]. Specifically, follow-up care should include screening for and diagnosing late effects, review of disease treatment and history, plan for long-term surveillance, coordination of sub-specialists, provision of psycho-social support, counseling on education and occupation, coordination of transition to adult care, education and outreach to survivors in the community, education of professionals (primary care providers, educators), and research. A survey of 24 directors of comprehensive pediatric survivor programs conducted in 2002 by Aziz et al. [18], identified similar components for ideal survivor programs and also suggested the following three area to improve the delivery of survivorship care: enhanced financial resources; expanded capacity for risk based care, especially psycho-social, and enhanced research efforts. Although survivor clinics have been developed at the majority of institutions that provide pediatric oncology services in

the United States little is known about the scope of clinical services provided, and challenges to meeting care goals.

In this study, we surveyed all the pediatric oncology programs in the New England region, encompassing geographically, and socio-economically diverse populations of childhood cancer survivors. Our aim was to assess the current state of survivor care and to identify challenges and common areas for improvement.

METHODS

Cohort

The Consortium for New England Childhood Cancer Survivors (CONNEXCS) is a group of healthcare providers (pediatric oncologists, pediatricians, other pediatric sub-specialists, psychologists, social workers, nurse practitioners, and nurses) with a clinical or academic interest in childhood cancer survivorship from all of the 12 academic medical centers in the New England geographic region of the United States that have pediatric oncology services. Member programs include Connecticut Children's Hospital, Hartford, CT; Yale Cancer Center, New Haven, CT; Dana Faber Cancer Institute, Boston, MA; Massachusetts General Hospital, Boston, MA; Floating Hospital for Children Tufts-New England Medical Center, Boston, MA; Bay State Medical Center,

¹Dana-Farber Cancer Institute and Children's Hospital, Boston, Massachusetts; ²Vermont Children's Hospital and Fletcher Allen Health Care, Burlington, Vermont; ³Yale Cancer Center, New Haven, Connecticut; ⁴Hasbro Children's Hospital, Providence, Rhode Island

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*Correspondence to: Lisa B. Kenney, MD, Dana Farber Cancer Institute, D321, 44 Binney St., Boston, MA 02115., E-mail: lisa_kenney@dfci.harvard.edu

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Springfield, MA; University of Massachusetts Medical Center, Worcester, MA; Eastern Maine Medical Center, Bangor, ME; Maine Children’s Cancer Program, Scarborough, ME; Dartmouth Hitchcock Medical Center, Hanover, NH; Hasbro Children’s Hospital, Providence, RI; and Vermont Children’s Hospital and Fletcher Allen Health Care, Burlington, VT.

Data Collection

A self-administered survey was distributed by electronic mail to each of the 12 pediatric oncology centers that are part of CONNECCS. The respondents were all Pediatric providers who had a leadership role in survivorship care at participating institutions including—Pediatric Oncologists (9), Pediatric Nurse Practitioners (2), Pediatrician (1), and Pediatric Registered Nurse (1). The survey included questions about the structure of the survivor services, survivor related clinical practices, finances, record keeping, educational programming, research, and advocacy.

Data Analysis

Analysis was based on the response of 13 clinics that provide pediatric oncology survivor services at 12 institutions (one institution has a program for pediatric brain tumor survivors in addition to a general pediatric cancer survivor program). Responses to each item of the questionnaire are summarized with descriptive statistics including means, medians, distributions, and 95% confidence intervals.

RESULTS

Characteristics of Pediatric Oncology Services

The 12 institutions represented have a median of 34 new pediatric oncology patients diagnosed annually (range 10–250) (Table I). On average, 4 programs treat fewer than 30 newly diagnosed children a year, 4 institutions treat between 40 and 55 children per year, and the remaining 4 programs treat between 65 and 250 newly diagnosed children a year. All but two institutions have a designated survivor clinic. The 2 institutions without a designated program have the fewest number of new diagnoses a year (10 and 20) and integrate survivor follow-up care into their pediatric oncology clinics. The largest service has 2 distinct survivor programs, one exclusively for brain tumor survivors. Of the 12 services, 8 “always” recommend annual follow-up for patients off therapy, 3 “usually,” and 1 “not always.”

Characteristics of Survivor Programs

The frequency with which the 11 survivor clinics meet varied across the region and is not necessarily reflective of program size. Of those with designated survivor programs, clinics are held once (5) or twice (1) monthly, or weekly (5). Given the complex nature of survivor visits, a median of only 6 (range 2–12) patients are seen during each session. Most programs (7) report that all survivors treated at their institution are seen in their survivor program and fewer (4) institutions report that not all survivors are referred to their clinic. Eligibility for the survivorship program varies by institution, most programs (7) enroll patients 2–3 years after completion of therapy; the remaining (4) wait until 5 years after completion of therapy. Although 6/11 programs do not have a specific age after

TABLE I. Characteristics of Pediatric Oncology Clinical Services in the New England Region and Established Pediatric Cancer Survivor Follow-Up Programs

	Institutions (N = 12)
Patient volume	
New pediatric cancer diagnosis per year, median (range)	34 (10–250)
<30 new diagnoses per year, n (%)	6 (50)
30–60 new diagnoses per year, n (%)	3 (25)
>60 new diagnoses per year, n (%)	3 (25)
Designated survivor clinics, n (%)	10 (92)
Survivor care during general oncology session, n (%)	2 (8)
Recommended yearly follow-up, n (%)	9 (75)
Designated survivor clinics (N = 11)	
Survivor clinic	
Location	
Pediatric oncology clinic (n, %)	11 (100)
Staffing (n, %)	
Pediatric oncologist	11 (100)
Nurse practitioner	7 (64)
Primary care provider	3 (27)
Register nurse	5 (45)
Mental health provider	9 (81)
Pediatric sub-specialist	3 (27)
Clinic sessions per month, n (%)	
one	5 (46)
2–3	1 (8)
4 or more	5 (46)
Survivors per session, median (range)	6 (4–12)
All survivors are seen in survivor clinic, n (%)	7 (64)
Patient population served	
Eligible for survivor clinic, years from completion of therapy, n (%)	
2–3 years	7 (64)
5 years	4 (36)
Transfer survivors to adult care	
Specific age, n (%)	4 (36)
Age at transfer (years), median (range)	33 (21–40)
No specific policy, n (%)	7 (64)
Financed, n (%)	
Foundation/private	5 (46)
Institutional	8 (73)
Fee for service only	2 (18)

which survivors could not be seen in the pediatric program, the 5 other programs had age maximums ranging from 21 to 40 years. All programs (11/11) usually refer survivors back to the treating oncologist for relapse of primary cancer.

All survivor clinics were staffed by pediatric oncologists (11/11), as well as other medical providers including nurse practitioners (7/11), primary care providers (pediatrician, internist) (3/11), or both (1/11). In addition, the majority of programs (9/11) have mental health services available as part of survivor care including psychologists (2), social workers (5), or both (2). Only 3 programs have sub-specialty providers integrated into survivor clinic.

Electronic databases are used to capture data on the survivor population in 8/11 programs; however, only 2 databases are linked to electronic medical records. Financial resources for the activities of the program are derived from a variety of sources including

professional fees only (2), foundation/private (5), and institutional budgets (8).

Follow-Up Services Provided

As shown in Table II, all survivor programs (11) recommend monitoring and screening for late effects. The COG guidelines [19] recommendations were used to guide clinic practice to varying extents: “always” at 5 programs, “usually” at 4 programs, and “sometimes” at 2. All programs provide their patients with printed treatment summaries and follow-up care plans. The timing of when patients receive this information varied, 4 institutions provide patients with this information as patients transition to survivor clinic, and 7 institutions both when the patients complete therapy and again when they enter survivor care. Although the majority screen for late effects as part of their survivor care, only 1 institution reports usually treating late effects in the survivor clinic, 2 clinics sometimes treat, and the remaining programs refer patients to sub-specialist to manage late effects. The most common sub-specialty referrals reported by providers, in order of frequency, are endocrinology, cardiology, and neuropsychology. Other specialists frequently referred to include pulmonary, orthopedics, gynecology, ophthalmology, and audiology.

Transition to Adult Care

Age is the criteria used by 4 survivor programs in the NE region, to transfer young adult survivors of childhood cancer to adult clinical

services, and 7 have no specific criteria or policy. Of the programs using age as the criteria for transfer, median age at transfer was 32 years, range 21–40 years. Two programs transfer to specialized adult cancer survivorship programs affiliated with their institution and two to adult primary care providers. All seven of the pediatric programs that did not report a systematic approach to transitioning young adult survivors of childhood cancer to adult care, reported that they saw all survivors of childhood cancer for survivor-directed care with no upper age limit, and four of these programs report that transitioning older survivors to adult care is a concerning issue for their program.

Education, Outreach, Advocacy, and Research Programs

More than half of the programs report having educational activities related to childhood cancer survivorship primarily for their colleagues or staff in the form of grand-rounds. As shown in Table II, education activities specifically for survivors were only reported by 3 programs and 3 programs reported educational activities directed at primary care providers. Also shown in Table II, 5 programs reported childhood cancer survivor research activity. Of those, the funding for the research was from private sources (2), government funding (2), and (1) both. Other than survivor celebrations and educational programs none of the institutions report advocacy specific survivor activities.

DISCUSSION

The results of our study show that the majority of pediatric oncology programs, in New England have established designated survivorship programs which meet national guidelines for clinical services. This data is particularly relevant in that institutions across the entire region were included in this study, representing pediatric oncology services which range in size from the smallest programs to the largest programs in our country, serving urban, rural, and minority populations. Although it is encouraging to document the universal availability of survivorship care, common challenges were identified including the transfer of young adult survivors from pediatric to adult care, managing the volume of sub-specialty care referrals, survivor education, and participation in research activities. In addition, resource intense survivor care remains difficult to fund, with survivor programs relying on combinations of philanthropy and foundations to supplement the revenues from fee for service billing.

The majority of programs in this study recommend annual risk-based follow-up for all survivors, consistent with published recommendations [13,17,20]. However, there is variability in the time of eligibility for to survivorship programs ranging from 2 to 5 years after completing therapy. Data from the Childhood Cancer Survivor Study (CCSS) show that by 5 years from diagnosis, 25% of all eligible survivors were already lost to follow-up. Of those enrolled in the CCSS cohort less than 50% were in regular follow-up, and increasing interval from diagnosis was correlated with decreasing likelihood of remaining in follow-up care [21]. These data suggest that the interval between the end of primary oncologic care and the initiation of survivorship care may influence loss to follow-up. In response, some pediatric services are instituting “transition” programs to bridge the gap between completion of active therapy and entry into survivor care with the aim of reducing loss to follow-up [22]. Retention in long-term follow-up is an

TABLE II. Clinical Services, Educational Activities, and Research Programs That Are Part of Pediatric Cancer Survivor Programs

	Survivor programs (n = 11)
Services provided	
Treatment summary, n (%)	11 (100)
Follow-up care plan, n (%)	11 (100)
Follow COG guidelines, n (%)	
Always	5 (46)
Usually	4 (36)
Sometimes	2 (18)
Timing of treatment summary, n (%)	
Completion of therapy	4 (36)
Entry into survivor clinic	11 (100)
Manage late effects, n (%)	1 (9)
Manage recurrence, n (%)	2 (18)
Most common sub-specialty referrals, n (%)	
Endocrine	11 (100)
Cardiac	10 (91)
Neuropsychology	7 (64)
Pulmonary	3 (27)
Other	4 (36)
Survivor educational programs, n (%)	
Faculty/staff	5 (46)
Primary care provider	2 (27)
Survivors	3 (18)
Survivor research	
Institutional protocols	5 (46)
Research funding	
Private funding	2 (18)
Government funding	2 (18)
Both	1 (9)

objective that will be examined in a subsequent analysis of our consortium programs.

Our data show that transitioning young adult survivors of childhood cancers to adult providers is an ongoing challenge for pediatric survivorship programs. Questions remain about the criteria to transition survivors to adult care as well as what type of adult provider (oncologist, primary care provider, and sub-specialist) is most suited to address their ongoing medical needs. Studies that have analyzed the transfer of young adults with childhood onset oncologic and non-oncologic disease to adult care identified the following barriers: adult provider lack of knowledge and training about pediatric disease, continued involvement of the young adults family, limited time during clinical encounters, and limited resources [23–26]. A survey study of 227 adult primary care providers by Bober et al. [27], showed that only 24% meet parameters for providing multidimensional follow-up to adult survivors and almost half (47%) feel inadequately prepared to provide survivor care. Defining and testing programs to facilitate the transfer of survivor health care services from pediatric to adult providers, in a variety of clinical settings, with the aim of optimizing long-term follow-up is the subject of future consortium studies.

Sub-specialty referral to evaluate abnormal screening tests or to manage late effects diagnosed in childhood cancer survivors is common practice in all of the programs surveyed. Although survivor programs in our study frequently used COG guidelines to inform screening and diagnoses of late effects, we found that providers rely on sub-specialty consultation to evaluate abnormal findings. This practice necessitates an available network of sub-specialists as well as administrative support. CONNECCS is currently developing regional consensus based clinical practice guidelines (CPG), which expand upon the current COG guidelines, by providing recommendations for the evaluation of abnormalities commonly found on routine screening tests such as thyroid function tests, and echocardiograms. The availability of CPG's will potentially facilitate sub-specialist evaluation as well as reduce unnecessary consultations.

Almost half of the institutions in the region have research programs specific to childhood cancer survivors. Of the 5 programs that reported research activity, 2 received government support and the remainder we funded by private or foundation donation. Participation in research is a survivorship program goal that is particularly challenging for smaller programs which do not have the patient volume or personnel to support such activities. Survivor oriented educational activities were not reported by the majority of programs surveyed. Finally, the allocation of financial resources to support comprehensive survivorship care is a common concern of programs, with two programs in the region receiving no additional funding to provide survivor services. Additional objectives of our regional collaboration are to provide opportunities for all institutions to participate in co-operative research protocols, to share educational resources and programming, and possibly financial resources to collectively improve survivor care.

Childhood cancer survivor programs in the New England region are making significant progress toward meeting the recommendations put forth as the ideal components of follow-up care systems, although some challenges remain to optimizing care. Specific barriers identified by this study include high volumes of referrals to sub-specialty care providers; transition of young adult survivors to adult clinical services; survivor education; participation in research; and funding for resource intense clinical programs.

Ideally, regional collaboration will serve to address some of the unmet clinical needs of survivors by refining referral practices, expanding networks of sub-specialty providers, developing successful transition programs, and by consolidating educational programs and research activities with the long range goal of advance the science of survivorship.

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