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Perspective

Time to establish multidisciplinary childhood cancer survivorship programs in Korea

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ABSTRACT

Improved treatment strategies and better supportive care have resulted in increased survival rates for childhood cancers. However, most of the survivors may have complex, long-term health issues. In 2004, Childhood Cancer Survivorship Study of the United States confirmed that both survivors and the medical community need to be educated about the late effects of childhood cancer treatment. Korea, with an estimated number of childhood cancer survivors of 20,000 to 25,000, faces similar challenges that the United States had experienced earlier. Despite of the tight budgetary situation on the part of government and hospitals, nationwide cohort study for Korean childhood cancer survivors was proposed and the versions of instruments to measure the quality of life of childhood cancer survivors were already validated. Nationwide registry of long-term survivors as well as the multi-center study is to be developed not only for the care of the survivors but also to raise the patient's awareness of the importance of regular follow-up. In addition to education of primary care providers regarding the survivorship, the need for special education program in the school system is emphasized.

INTRODUCTION

Improved treatment strategies and better supportive care have resulted in increased survival rates for most childhood cancers. Currently, close to 80% of children and adolescents with cancer will survive 5 years or more after diagnosis. In the USA, nearly 300,000 childhood cancer survivors are now alive. This represents 1 : 640 adults aged 20-39 years old. Most of the survivors may have complex, long-term health issues [1]. They are at risk for developing secondary neoplasm, cancer recurrence, organ dysfunction, impaired growth and development, decreased fertility, impaired intellectual function and dental problems as well as psychosocial, behavioral problems and post traumatic stress disorder [2, 3]. Their life expectancy is also reduced by as much as 28% [4]. Naturally, many survivors become uncomfortable and anxious about their health and unsure of how to cope with life for months and years after treatment.

Listed in the Table 1 are the several very informative policy reports and recent publications regarding the childhood cancer survivorship issues that had subsequently ignited the subsequent studies on survivorship in the United States and that had initiated setting up the survivorship clinics in many cancer centers [5, 6].

CANCER SURVIVORSHIP PROGRAMS

In 2004, Childhood Cancer Survivorship Study funded by National Cancer Institute (NCI) grants confirmed the somber facts that long-term late effects are common, that severe disabling or life-threatening conditions may occur and psychosocial and behavioral problems may also be present. The study also pointed out that both survivors and the medical community need to be educated about these dreadful late effects of childhood cancer treatment. This had set the stage for establishing survivorship centers across the United States to better evaluate the survivors for appro-

Table 1. Recent policy reports and publications regarding the childhood cancer survivorship.

1. The President's Cancer Panel Annual Report:
In 2003-2004: Living beyond Cancer; Finding a New Balance
2. Institute of Medicine (IOM) Reports:
In 2003-Childhood Cancer Survivorship: Improving Care and Quality of Life
In 2006-From Cancer Patient to Cancer Survivor: Lost in Transition
In 2007-Implementing Cancer Survivorship Care Planning
3. Childhood Cancer Survivor Study Reports:
In 2004-Health Care of Young Adult Survivors of Childhood Cancer
In 2006-Chronic Health Conditions in Adult Survivors of Childhood Cancer [5]
In 2010-A Model-Based Estimate of Cumulative Excess Mortality in Survivors of Childhood Cancer
4. The Centers for Disease Control and Prevention:
In 2005-A National Action Plan for Cancer Survivorship: Advancing Public Health Strategies
5. Cure Search/Children's Oncology Group (COG):
In 2007-Long-term Follow-up Program Resource Guide
6. American Academy of Pediatrics:
In 2009-Long-term Follow-up Care for Pediatric Cancer Survivors [6]

appropriate care and offer education of the patients and primary health care providers. To this end, several U.S. State cancer grants and some private grants, particularly the Lance Armstrong Foundation Awards had funded a number of survivorship centers. One such funded program is the Cancer Survivorship Center established at Emory University in Georgia that I am personally familiar with. While it provides coordinated multidisciplinary cancer-focused care for the patients as well as clinical research on survivorship issues, the program offers education to health care professionals in the State of Georgia through lectures, consultations and CME videos. The program recently established the "Survivor Link", also named the Georgia Pediatric Alliance Cancer Survivors. Through this network which includes patients, primary health care professionals and the cancer center specialists, the primary health care professionals get much needed education regarding the survivorship health issues and every pediatric cancer survivor in Georgia receives a comprehensive Survivorship Health Care Plan as per Children's Oncology Group (COG) guidelines coordinated by the Emory cancer survivor team staff. This could be a model for the similar programs to be established in Korea.

COG INITIATIVES

Recognizing that survivorship is an important phase of cancer care, the COG made a decision to merge the previous Late Effects Committee and the Cancer Control Discipline into one entity. In the past, the Late Effects Committee's role was mainly to gather all the necessary information on the survivors; thus its function was largely observational

in nature. The Cancer Control Discipline on the other hand had been interventional in nature with the research studies conducted throughout prevention, diagnosis and treatment phases. By merging the two, the COG is more streamlined in conducting the research to prevent cancer, reduce acute toxicities, improve symptom management and reduce morbidity and mortality in survivors of all childhood cancer. In short, the new combined committee (Cancer Control and Long-term Survivorship, CCLS) works on improving health across the trajectory of childhood cancer from before diagnosis through long-term survivorship and end of life care.

One of the major accomplishments of COG is that it has established a guideline for the long-term follow-up of childhood cancer survivors which can be viewed at www.survivorshipguidelines.org. It serves as a helpful resource both for cancer institutions and primary health care professionals alike in carrying out comprehensive yet standardized follow-up care for the survivors.

COG now conducts a number of studies dealing with survivorship issues. One is ALTE03N1 protocol: Key Adverse Events after Childhood Cancer. The focus of investigation is to identify treatment-related risk factors in relation to genetic susceptibility of the individuals. The protocol mandated obtaining blood or buccal samples to study the frequencies of gene polymorphism among the survivors who developed key adverse events such as cardiac dysfunction, ischemic stroke, avascular necrosis and subsequent malignant neoplasms. Another important study is ALTE05N1: Umbrella Long-term Follow-up Protocol that was activated on 5/19/08 and so far has accrued 262 patients out of a target sample of 5,000. Main theme of this study is that one single center is designated to collect health care information, and later the designated institution is to distribute the information to each patient's COG institutions. The Long-term Follow-up Center located in the Keck School of Medicine at the University of Southern California maintains up-to-date demographic and self/parents-reported health status information on each patient and provides updated data to the COG Statistics and Data Center (SDC) on a regular basis, and the SDC will subsequently forward this information to each patient's COG institutions in conducting follow-up examinations and collecting protocol specific data. These data can then be linked with patients' outcomes, facilitating identification of important associations and concerns for outcomes research.

SPECIAL CHALLENGES IN EDUCATING THE PRIMARY CARE PROVIDERS

Given the complex medical, psychological and behavioral problems experiencing by the childhood cancer survivors, it is imperative that they receive long-term follow-up care from the health care providers knowledgeable with the long-term survivor issues. The eventual goal of cancer treatment is not only to ensure the patient's long-term survival

but also to help them to maintain physical and psychological health status to function as normally as possible at home, in school and in the work place. One major problem in dealing with the survivorship issue is that it's not easy to find the proper health care professional to care for the survivors. As the childhood cancer survivors age out of the pediatric health care system, family physicians and internists who are generally not familiar with the complexity of the pediatric cancer treatment are often called to provide long term care. Therefore, it is imperative that the multidisciplinary team at each cancer survivor center work as closely as possible with the community based health care providers.

SURVIVORSHIP ISSUES AND CHALLENGES FACING KOREA

In the late 1980's and 90's, a number of modern Pediatric Oncology Departments in Seoul and around the country were established. These departments were regularly staffed with pediatric oncologists trained mainly in the USA by way of educational tours during their sabbatical year. As a result, the children in Korea began receiving state-of-the-art cancer care for more than 20 years now. This resulted in remarkable improvements in survival statistics that are nearly comparable to those of western countries. It is to be emphasized that the success of childhood cancer care in Korea could have not come without the dedicated support of families, and hosts of other care providers working in the hospital side by side with the doctors. At the time of the governmental budgetary constraints, numerous philanthropic donations from individuals and groups also contributed. It is commendable that in recent years, the Korean government has increased the budget allocations for the families of children with cancer. This eased the financial burden on the families that, in turn, has enabled families to seek cancer care more freely.

In Korea, the annual incidence of cancer in children and adolescents is 1,700 with the 5 year survival rate of 70% in the year of 2001 through 2005, with the result that close to 1,200 children and adolescents with cancer currently enjoy long-term survival. Hence, the cumulative number of childhood cancer survivors living in Korea is estimated to be around 20,000 to 25,000 [7, 8]. Korea faces similar challenges that the United States had experienced earlier. These include starting the registry of long-term survivors, need for long-term follow-up studies, establishing a cancer-focused multidisciplinary team in the cancer center, raising the patient's awareness of the importance of regular follow-up, education for primary care providers regarding the survivorship, and the need for special education program in the school system. In addition, the tight budgetary situation on the part of government and hospitals adds to the challenges. These are only a few things that come to my mind. However, I see some unique strength in Korea as opposed to other countries. First, Korea is relatively small

geographically, and the transportation system is in place so that patients should be able to travel in a relatively short time to receive cancer focused follow-up care practically anywhere in Korea. Second, children with cancer have been treated in only a handful of pediatric cancer centers. This means that the patients' hospital records are more retrievable. Third, there's unity among all the pediatric oncologists in terms of working together for the same cause, namely nationwide multi-center studies.

It is encouraging to note that the nationwide cohort study for childhood cancer survivors was already proposed, and the versions of instruments to measure the quality of life of childhood cancer survivors were validated [9, 10]. Further, the meeting of the childhood cancer survivors in Korea also took place for the first time early this year. One of the biggest challenges and the utmost importance is setting up the weekly multidisciplinary cancer-focused survivorship clinic in major cancer centers to be staffed with pediatric oncologists, pediatric endocrinologists, pediatric neuro-oncologists, neuro-psychologists, and other pediatric specialists. The cognitive, endocrine and the imaging studies are ideally to be done in the same setting when the patients come in for their regular check-ups. In spite of all these hurdles and hardships, I salute the leadership of Korean Society of Pediatric Hematology/Oncology for setting up the survivorship issues as one of top priorities.

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