

Psychosocial aspects of childhood cancer survivors

Jong Jin Seo, M.D.

Department of Pediatrics, University of Ulsan College of Medicine, Seoul, Korea

= Abstract =

The majority of childhood cancer survivors and their families will be psychologically healthy, but may desire and benefit from preventive care. A significant portion of the survivor population will be psychosocially distressed in various aspects by their harsh experience of long cancer treatment, and may warrant professional intervention and treatment. Pediatricians should be aware of the late psychological effects that can occur a year or 2 after treatment, possibly in many aspects of a survivor's life. Not only the cancer diagnosis, but also treatments such as chemotherapy, irradiation, and surgical intervention may exert different long-term effects on the psychosocial outcomes of survivors. Pediatricians need to be more concerned with maintaining and improving the psychological health of this growing number of childhood cancer survivors through long-term follow-up clinics, community support, or self-help groups. Research on all of the psychosocial aspects of childhood cancer survivors is important to recognize the reality and problems they face in Korea. (Korean J Pediatr 2010;53:471-476)

Key Words: Childhood cancer, Survivor, Psychosocial aspect, Psycho-oncology

Introduction

Before I go on to review the psychosocial aspects of childhood cancer survivors, I have to mention a couple of things for the correct understanding of the Korean situation on this topic. Regretfully, interest in this important field is now beginning in Korea, and there had been few studies on this subject in Korea. As we have little Korean data, I had to rely on the previously reported data from western countries in all aspects of psycho-oncology, which may be somewhat different from what is occurring in Korea.

While preparing this review, I realized that we should research the psychosocial aspect of childhood cancer survivors in Korea in order to improve our knowledge and understanding of the psychosocial issues affecting Koreans who have survived childhood cancer. For this purpose, the Korean Society of Pediatric Hematology-Oncology (KSPHO) has recently supported the establishment of an assembly of childhood cancer survivors (the name of which is not yet decided), as well as a parents' assembly, the Korean

Childhood Cancer Parent Organization (KOCCPO), which is a gathering of parent representatives of each hospital from which their children were treated. The KSPHO is also preparing to publish a comprehensive guidebook on long-term follow-up care for childhood cancer survivors, for which the psycho-oncological issues of childhood cancer survivorship will be an important part.

With the great advances in the field of pediatric hematology-oncology during the past few decades, the average cure rate of childhood malignancies now approximately 70%, creating a large and growing population of young people who are successfully off treatment. It was estimated that by the year 2000, about 1 in every 900 young adults would be a survivor of childhood cancer.

Like late medical effects, late psychological effects can occur a year or 2 after treatment, and may not even begin to emerge until many years after treatment ends, appearing in many aspects of a survivor's life. Not only the cancer diagnosis, but also the treatments, such as chemotherapy, irradiation, and surgical intervention, may exert different long-term effects on the psychosocial outcomes of survivors.

Childhood cancer survivors and their families have to manage many transitions that accompany the end of treatment. They have to mind continuing medical screening

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Corresponding Author: Jong Jin Seo, M.D.

Department of Pediatrics, University of Ulsan College of Medicine, Asan Medical Center, 388-1 Pungnap-2dong, Songpa-gu, Seoul 138-736, Korea
Tel: +82.2-3010-3383, Fax: +82.2-473-3725

E-mail: jjseo@amc.seoul.kr

for recurrence of cancer as well as the emergence of late medical and psychological effects.

Psychological symptoms in childhood cancer survivors

While parents tend to notice higher than average levels of somatic symptoms in children¹, most research indicates little is unusual in the levels of psychological symptoms in survivors during childhood and adolescence. The overall rates of depression², behavioral disorders^{1, 3}, and other general psychological symptoms⁴⁻⁶ reported by children and their parents have been comparable to those reported by children who have never had cancer. Only brain tumor survivors showed higher levels of depression and other presumably organic disorders, as well as a higher rate of psychiatric hospitalization⁷.

Although most survivors are not depressed and report that they are doing well overall, a significant minority may experience some form of significant psychological distress^{5, 8, 9}. It is important to note that these high levels of psychological distress are evident even in groups of survivors who also report good overall functioning, with high rates of employment, and high scores in quality of life measures¹⁰. One alternative is to view cancer as a traumatic event, which may in turn lead to the experience of post-traumatic stress during the survivorship years^{11, 12}.

At diagnosis, parents are told explicitly that their child may die. Cancer treatment can be a horrifying, scary, and painful series of events for everyone involved, ranging from events like hair loss to repeated painful invasive procedures.

Post-traumatic stress reactions to these distressing events can be initiated immediately after the initial traumatic event and continue for many years. Three kinds of post-traumatic stress symptoms (PTSS) may emerge: persistent re-experiencing of the traumatic parts of cancer/survivorship (including nightmares or strong negative feelings triggered by reminders), actual or considered avoidance of cancer- or survivorship-related situations, and strong physiological responses when reminded about cancer or survivorship^{13, 14}. Survivors may experience only a few of these PTSS, or they may develop several symptoms from all 3 categories. If this happens and if the symptoms significantly interfere with their normal activities, the diagnosis of post-traumatic stress disorder (PTSD) is warranted. Rates of PTSD for adolescent sur-

vivors are generally low, however, most adolescent survivors do report at least some symptoms of PTSD^{15, 16}.

Cancer and survivorship can be traumatic not only for the survivor, but also for family members, and parents and siblings experience PTSS and PTSD¹⁷⁻¹⁹.

Parents and survivors frequently explain that childhood cancer taught them to see things in positive ways that other people do not do, that they are not as materialistic and that they are more empathic. Survivors frequently feel that they are more mature than others of their age, and that they value their family relationships more. Family members and survivors may feel grateful to the medical professionals who worked with them, and proud of their ability to manage and survive challenges like childhood cancer and survivorship¹⁷.

Quality of life issues in childhood cancer survivors

Adolescent and young adult childhood cancer survivors report very good overall functioning in physical and general psychosocial domains^{10, 20, 21}. Only 2 quality of life issues appear to emerge as consistent areas of difficulty for survivors: the experience of ongoing fatigue or pains, and anxiety over late medical effects or the possibility of a second cancer²¹. Mothers report a greater negative quality of life for their adolescent survivors than survivors report for themselves, suggesting the importance of asking children and their mothers independently about quality-of-life issues.

Brain tumor survivors report a lower physical quality of life than survivors of other cancers, while there is some evidence that survivors of acute lymphoblastic leukemia, who report good physical quality of life, may have more psychosocial issues²⁰. However, the average levels of quality of life across studies indicate that survivors have a positive outlook, are satisfied with their lives, feel a sense of purpose, and have the same opportunities on daily living as do their never-ill peers.

Studies documenting the impact of childhood cancer on educational and employment achievements, as well as on the achievement of developmental milestones, are largely consistent with these generally high levels of quality of life²²⁻²⁴. Some survivors, however, appear to be at greater risk for difficulties in these areas. Those treated before the age of 6 who survived a brain tumor, or who received intrathecal methotrexate and/or cranial radiation (espe-

cially at doses higher than 24 Gy) are more at risk for learning disabilities and special education placements, and are less likely to finish high school and complete a bachelors degree^{22, 23}.

Later differences in employment may also be evident in some survivors, despite overall high rates of employment in survivors generally. Survivors appear to be employed less frequently than their siblings²⁴, although more survivors than siblings report being students or homemakers²³.

As many as one-third of all survivors report problems obtaining health insurance, a potentially significant problem in this medically-vulnerable population. Rates of marriage are also generally high, although there is evidence that survivors marry at rates lower than those of their siblings or the population norms. Those with CNS tumors appear to have lower marriage rates and, when they do marry, have higher divorce rates^{23, 25}.

Effects on social development

Developing social relationships is a primary task of childhood and adolescence. Because cancer and treatment at least partially remove children from the normal everyday activities in which most children build relationships, it seems likely that social development is an area at risk for difficulties.

While childhood cancer survivors do show some social developmental differences, it is not clear that these differences represent deficits. Overall, survivors of childhood cancer are rated as more socially isolated and they have fewer best friends than do other children²⁶.

Being less involved with peers may not give survivors the social practice they will need as young adults. These kinds of difficulties are likely to emerge slowly over time, and they might not be evident until several years after treatment ends. Indeed, 1 study suggests that in adulthood, childhood cancer survivors have more difficulty with close friendships and romantic relationships, and develop shorter intimate relationships and relationships that lack disclosure or personal involvement^{27, 28}.

CNS malignancies appear to present a specific vulnerability for late psychological effects beyond the cognitive changes that are usually associated with CNS disease and treatment. This vulnerability appears to be particularly associated with deficits in social development. Several studies on children who were treated for brain tumors have

identified difficulties in social competence and communication with peers; they also cite reports of social isolation^{29, 30}. It is likely that compromises in social competence are related to the cognitive changes that many brain tumor survivors experience because of their disease and treatment³⁰. Over time, these survivors are at higher risk psychologically, and are significantly more likely to experience psychiatric hospitalization and to demonstrate a higher risk of psychotic illness after physical illness⁷.

There is very little research on the social consequences of childhood cancer for the survivors family. Some research suggests that parents may feel lonely or isolated after treatment ends³¹. Medical support is less frequent after therapy ends, while friends and family members may not understand a parents continued medical concerns. Being aware that these feeling can emerge, and finding new ways to talk to those in their support network about the stage of cancer survivorship can help parents feel more connected and less isolated.

The self-help parents gathering of childhood cancer survivors and that of survivors themselves can also help to reduce this feeling of isolation.

Implications of long-term follow-up clinic

Programs oriented to the individuals needs of each long-term survivor of childhood cancer must begin when the childhood cancer patients go off therapy. The physician possibly with a nurse, should meet the family and the patient according to age to review the past and plan the future. It is the responsibility of the pediatric oncologist to provide the survivor and parents with a clinical summary after completion of treatment. The summary must suggest the type and timing of the follow-up evaluations to monitor the original cancer as well as possible late effects of the disease and its treatment.

A specialty clinic oriented to the preventive medical and psychosocial care of long-term survivors should preferably be managed by the pediatric oncologist who treated the child, and should have available a multidisciplinary team based on the individual patients needs. Personalized programs should monitor each long-term survivor for special conditions related to their unique history, as well as their normal developmental concerns. Programs should include psychological counseling for young people experiencing adjustment difficulties and physical rehabilitation programs

for survivors with significant side effects³²⁾.

Participation in regular follow-up care is strongly recommended for long-term survivors in order to provide prevention and/or early detection of late medical effects^{33, 34)}. Since childhood cancer survivors do well overall and demonstrate relatively low levels of psychological symptoms, it is easy to overlook psychosocial issues that can interfere in the survivors medical care. However, even low-to-moderate levels of post-traumatic stress can have very significant medical consequences³⁵⁻³⁸⁾.

Participating in follow-up care itself can be a source of distress. Survivors may be retraumatized as they hear about medical complications associated with their treatment, and long-term survivors and their family members report follow-up visits to be among some of the most frightening moments they experience¹⁷⁾.

Childhood cancer survivors may not have had full access to information during their treatments, and often learn of their long-term medical risks for the first time during a follow-up visit³⁹⁾. Furthermore, as childhood cancer survivors reach adulthood, they take on the direct responsibility of managing their own healthcare formerly handled by parents, which can be overwhelming and frightening.

Followup care can definitely help to mitigate the psychosocial issues that can emerge during survivorship^{34, 40-42)}. Recommendations include comprehensive, but brief psychosocial screening in every follow-up visit for every patient⁹⁾. Even brief educational interventions can be effective in changing survivors understanding of their medical vulnerability, as well as their perceptions about the importance of follow-up care⁴³⁾.

Conclusion

In general, survivors of childhood cancer report doing very well and demonstrate low rates of traditional psychological issues. Although most survivors do well, a significant proportion of childhood cancer survivors may experience PTSD, and most survivors and their family members experience at least some symptoms of post-traumatic stress related to cancer, treatment, or survivorship experiences. The large majority of these reactions are normal reactions to the unusual stress of childhood cancer. It is essential during any comprehensive follow-up care program that there be a sensitive assess-

ment of these issues and that the development of interventions to combat late psychological effects be a part of the ongoing efforts. We need our own data on every psychosocial aspect of Korean childhood cancer survivors to recognize the situations in Korea correctly^{44, 45)}.

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