

EDUCATIONAL GOALS AND ATTAINMENTS OF PEDIATRIC
CANCER SURVIVORS

by

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APPROVAL

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CANCER SURVIVORS

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ABSTRACT

In the past 35 years, pediatric oncology five-year survivorship has increased from 50 to 80%. As the number of survivors has increased, there has been increased interest in research investigating late effects of cancer treatment, such as cardiac abnormalities, pulmonary impairment and post treatment psychological disorders. The current study investigated educational and career difficulties experienced by adolescent and young adult cancer survivors who are at least one year off cancer therapy. A mixed methods single institution study using questions from the Childhood Cancer Survivorship Study (CCSS) questionnaire, a demographic data form, and a set of open ended questions was conducted from October 2013 through October 2014. Data analysis using SPSS version 19.0 was conducted via dichotomous variables using frequencies, and Chi Square analysis. A total of 50 survivors participated in the project. Quantitative findings suggest that having a Central Nervous System (CNS) tumor and receiving CNS radiation is associated with visual impairment post therapy. 28% of those who reported receiving CNS radiation also reported double vision ($X^2 = 11.040$, $p = .004$). A diagnosis of a CNS tumor was also associated with tinnitus, as 38% of those with tinnitus were CNS tumor survivors ($X^2 = 24.959$, $p=.035$). 4 of the 11 respondents reporting CNS radiation also reported balance difficulties ($X^2 = 14.023$, $p=.003$). Qualitative findings suggested four themes experienced by adolescent young adult cancer survivors: a polarized opinion on their future as medical professionals, a report of dreams fallen short due to therapy, an impact on peer relationships, and a positive outlook on life. Several respondents reported that extended interactions with health care providers either greatly increased or decreased their

wishes to enter the medical profession. Survivors also reported that physical or mental disabilities impacted their ability to later achieve their dreams. Respondents also reported difficulties with peer relationships due to extended time away from school and a change in their appearance. Finally, despite the challenges faced, the survivors reported increased positivity overall in their lives. Despite the limited sample size, results of the study display difficulties faced by CNS tumor survivors that warrant further research. The results also show that despite an extended period of missed school, the survivors did not display statistically significant difficulties with later education. Rather, the survivors focused on the difficulties of socialization post therapy. Future studies using larger sample sizes are warranted to further examine the socialization of childhood cancer survivors of CNS cancer.

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INTRODUCTION

According to the Survivorship, Epidemiology and End Results (SEER) data provided by the National Cancer Institute, the mortality rate for all childhood cancers declined by 40% from 1975 to 1995 (Ries et al., 1999). As the number of survivors has increased, childhood cancer survivors are faced with a myriad of late effects resulting from cancer and its treatment. Late effects include cardiac impairment, pulmonary impairment, and recurrence (Mertens, 2001). Along with physical side effects, survivors often experience psychological impairments such as Post Traumatic Stress Disorder (PTSD) (Hobbie et al., 2000) and depression as a result of surviving cancer (Zebrek et al., 2002). The adolescent and young adult (AYA) population may also have difficulty learning to navigate the working world after the extensive social isolation of their illness (Pang et al., 2008).

Background/Significance

Long term complications associated with a childhood cancer diagnosis include cardiac problems (Mulrooney et al., 2009), lung damage (Mertens et al., 2002), secondary cancer (Henderson et al., 2007), infertility (Barton et al., 2013), liver damage (Lansdale et al., 2010), growth and development disorders (Gurney et al., 2006) and impaired psychosocial and neurocognitive status (Zeltzer et al., 2008).

While the physical issues experienced by survivors post therapy are of great importance, the investigators who conducted the current study are interested in the reintegration needs of survivors into either school and/or how the cancer experience has molded their choices for higher education and career.

Literature Review

A literature review was conducted using the Childhood Cancer Survivorship Study (CCSS) publications, CINAHL, and Pubmed. The CCSS survey was devised for survivors of childhood cancer and results are available for investigators from a variety of institutions. Keywords used included “education,” “long term,” “cognitive impairment” “employment,” “adolescent,” and “survivor” (as well as combinations of these terms).

Cognitive issues are a significant side effect of chemotherapy and radiation therapy, especially because the brain is still developing connections for important activities like information processing and balance (Mitby et al., 2003). Mitby et al (203) studied the number of childhood cancer survivors that required special education post treatment in childhood compared to their siblings. They found that 23% of survivors reported needing some form of special education service post treatment, whereas only 6% of siblings reported needing these same services. Central nervous system involvement at the time of cancer diagnosis or treatment was a significant indicator of possible need for special education. Consequently, Mitby et al (2003) hypothesized that earlier diagnosis led to a higher likelihood for the need for special education, possibly because the brain is still forming.

In 2010, Whelan et al. explored the ocular late effects of childhood cancer, and found that childhood cancer survivors are at risk for glaucoma, double vision, cataracts, and legal blindness. This risk was validated when comparing the incidence of these conditions compared to the healthy siblings of survivors. Incidence of ocular disease was two to fivefold higher in the survivor cohort as compared to the healthy sibling cohort (Whelan et al., 2010).

Cognitive abilities after treatment can be an important indicator of employment potential. Survivors who suffer from memory problems after completion of therapy are less likely to be employed compared to survivors without memory problems (Kirchoff et al., 2011). These investigators also found that a better state of overall physical health after therapy leads to a higher likelihood of employment. Gender also was an indicator of employment post therapy, because males are more likely to experience a decline in overall physical health and memory and therefore have lower employment rates.

The physical appearance of the body is also an indicator of employment post cancer treatment. Nagarajan et al. (2003) compared the employment outcomes of pediatric bone cancer survivors (both amputee and non-amputee) to their healthy siblings. While no statistically significant differences exist between amputees and non-amputees, there is a significant difference in employment and education (OR = 0.2, p= .001) for amputees < 12 years of age compared to their healthy siblings.

Little is known about the long term psychological effects in adolescent survivors and those with central nervous system (CNS) tumors (Mertens et al., 2014). However, these survivors reported less favorable outcomes in the realms of satisfaction and psychological domains compared to survivors of non CNS malignancies. Females also had less favorable outcomes than males in the same realms. The authors recommend further study about the specific psychological effects. Brinkman et al. (2013) also examined psychological outcomes post cancer therapy and discovered that adult survivors were more likely to report psychoactive medication use compared to their healthy siblings. These authors concluded that more awareness of psychological outcomes is needed while these survivors are on treatment.

Despite a thorough review of the literature, the investigator identified a gap in the literature describing the educational goals and attainments of AYA cancer survivors. Although several studies have contributed to the understanding of the education and employment outcomes of childhood cancer survivors (Kirchoff et al., 2011; Mitby et al., 2003; Nagarajan et al., 2003) and clinical practice guidelines (Landier et al., 2013), gaps remain in our understanding of the impact of surviving cancer on these life events.

Methodology

Design

Following Institutional Review Board (IRB) approval, this mixed methods survey study was carried out using a combination of questions from the CCSS questionnaire (see Appendix A), a demographic data form (see Appendix B), and investigator developed open-ended questions. The open-ended questions asked survivors to reflect upon their cancer experience and how it influenced their later educational and career goals and attainments (see Appendix C).

Procedure

Potential participants were contacted first using a postal mailed survey explaining the project, a set of the project materials, and a self-addressed return envelope. The first mailing resulted in a poor return rate of only 33/259 (13%). In efforts to enhance the sample, the investigators expanded the cohort to include survivors diagnosed at age 12-18

years from 13-17 years of age. The second postal mailing yielded 8/359 (2%). Due to continued return poor returns, the IRB at Cook Children's Medical Center granted an amendment in April 2014 to develop a script for staff unaffiliated with the project to approach patients in clinic for participation. The script was read and patients were given the option to participate. This method yielded an additional nine participants for a total response rate of 14%.

Data Analysis

Statistical analysis was conducted using SPSS version 19.0. Dichotomous variables were analyzed using frequencies, and Chi-square test. Qualitative data was analyzed using content analysis. Content analysis is a way to analyze data using a system of coding and categorization. In this instance, the qualitative responses from participants were coded according to common themes, like health care experiences, feelings around friends, and feelings for the future. This analysis was done independently by both investigators and then together to enhance reliability in the themes.

Sample

Survivors who met the inclusion criteria of: diagnosis between the age of 12 and 18 years, over the age of 18 at the time of study, and had completed cancer treatment for at least two years were included in the study.

Setting

Survivors treated at a tertiary pediatric medical center in the south were identified using several methods including the survivor database, the electronic medical record, and the Passport for Care™

Results**Quantitative**

A total of 50 survivors participated in the project. The sample consisted of 29 (62%) men and 18 (38%) women. 39 of the participants were white (83%), two (4%) are African American, and six (13%) responded as “other,” primarily Mexican American. The remainder of the demographics for this population can be found in Table 1.

Based on the findings, having had a CNS tumor and having receiving radiation is correlated with visual impairment. In addition, having had a CNS tumor and receiving CNS radiation was associated with double vision. Three participants (28%) who reported having received radiation also reported double vision ($X^2 = 11.040$, $p = .004$).

Twenty survivors who reported missing at least one full semester or an entire school year actually received homebound education during this time, meaning they missed the socialization but not the actual education. ($X^2 = 12.924$, $p = .005$).

Specific diagnosis was statistically significantly associated with scarring of the face. Of the total six survivors who reported “yes” to scarring of the face, three were survivors of central nervous system tumors. ($X^2 = 18.293$, $p = .011$). Of the total eight survivors who reported yes to having tinnitus, three of those eight (38%) were CNS tumor survivors. ($X^2 = 24.959$, $p = .035$) Four of the 11 respondents who experienced CNS radiation also reported problems with balance that are still present. ($X^2 = 14.023$, $p = .003$).

The data analysis yielded no statistically significant data surrounding the study's question of educational goals and attainments in pediatric cancer survivors.

Summary

The quantitative findings revealed that survivors who received homebound education considered this education to be missing school time. This suggests that adolescents facing cancer consider the socialization part of the school experience to be as important as the educational aspect. The findings also suggested a relationship between CNS radiation and later problems with vision and balance. Further analysis was attempted with CNS tumor survivors only with the selective variables of memory, balance, and tinnitus, but the number of participants reporting this finding was too small to complete the analysis.

Twenty survivors (52%) reported working part time only. The sample consisting of a young adult population (mean age = 27.4 years), and many of these respondents may be students.

There were no statistically significant findings between employment and the personal demographics of this population. This may be due to the portion of the sample that are students or the sample size.

Qualitative

The open-ended response questions provided an opportunity for survivors to describe in the impact of their cancer experience on their lives in their own words. Through these open ended responses, four common themes emerged. The themes included future as medical professionals, dreams fallen short, peer relationships, and positive outlook on life.

Future as medical professionals. Adolescents undergoing cancer therapy spend many hours with healthcare professionals both in the hospital and the outpatient clinic setting. This amount of interaction can influence the adolescent's goals for life post treatment. Multiple survivors described an increase in interest in the medical field as a result of their cancer experience. Here are several of their comments:

“I'd like to go into medicine”

“I decided that I definitely wanted to go into health care.”

“I'd say it fundamentally changed what I wanted to do, and it meant becoming a doctor.”

“I wanted to work in healthcare or something to do with health and wellness.”

Unfortunately, several survivors also reported a desire to never enter another hospital again, whether as a patient or medical professional.

“I never wanted to go back to another hospital so I changed my career focus.”

“I also considered medicine for a short time, but ultimately decided against it. I figured that I had spent plenty of time in a hospital.”

While the responses varied in this way, the experience of cancer had some influence on the future career of respondents.

Dreams Fallen Short. Several patients discussed how cancer affected their abilities to pursue their dreams. While they may have had goals to be medical professionals, social workers, or military personnel, their abilities to obtain these goals were impacted by the experience of cancer.

“Losing my leg made it impossible for me to join the marines.”

“Cancer made me take a step back and see realistically.”

While these survivors reported dreams of engaging in specific career activities, clearly their cancer treatment affected their ability to be successful. Further, at least one survivor was able to assess the need to be more realistic in career choices because of the late effects of this cancer treatment.

Peer Relationships. The adolescent years are some of the most tumultuous years of life. Friendships are constantly changing, and adolescents are trying to figure out “who they are” (Jose & Sujatha, 2012). Physical appearance is of particular importance to this age group (Williamson, 2014). Adolescents simply want to fit in with the larger group, and spend more time in groups as opposed to individuals. Peer engagement and acceptance is paramount on this group. Because of treatment, adolescents with cancer often look different than their peers, for reasons such as steroid weight gain, weight loss, limb loss from amputations, and scars from multiple surgeries. This can make relating with peers and being accepted by peers difficult. The following comments depict the feelings of this group.

“It made me self-conscious.”

“I had body image issues.”

“Physical abnormalities made it a little difficult.”

Adolescents on cancer therapy often miss large amounts of school, making them miss out on the day to day happenings, which can cause them to feel as if they don't fit in

to the group. These statements are representative of the quantitative responses, and may be the same survivors who reported homebound education for at least a year.

Respondents reported that

“My friends did not know how to interact with me.”

“People treated me differently.”

The responses to the question of difficulty going back to school were different from expected. While the question was meant to glean information on possible academic difficulties of going back to school, respondents focused on the physical and social aspects.

Positive Outlook on Life. Despite the challenges they have faced, the survivors expressed an appreciation for life. Despite many changed career and educational trajectories, survivors found the positive side of surviving cancer. Multiple survivors stated that they consider themselves lucky despite challenges they may have faced or will face in the future.

“I feel that there’s a reason I’m still here.”

“Cancer taught me not to take life for granted.”

“I’m very blessed to be where I am and to have the health I have.”

Summary

The answers to the qualitative questions provided invaluable information surrounding the impact cancer has on the lives of young adults afflicted with the disease. While each survivor surveyed had a unique cancer experience, together their responses

indicated that overall cancer can influence whether or not a survivor enters the field of medicine, whether or not a survivor is able to achieve their career dream, causes some difficulty with peer relationships, and leaves the survivor with an overall positive outlook on life. Knowing these themes can assist a clinician to relate to the survivors he/she is treating.

When the authors of this study considered the career goals of adolescent cancer survivors, they were curious as to how the extensive interactions with medical professionals would influence their later career choices. The authors considered two hypotheses surrounding this question: that the experiences with health care professionals would polarize the individual survivors as either working hard to achieve a medical career or wanting nothing to do with the field in their career, and that treatment for cancer would have an impact on the survivors ability to achieve a medical profession if they desired one. Certainly, the sample proved that survivors do feel a polarization about a medical career; however, while some survivors responded that treatment made it difficult to achieve high enough grades to enter the medical profession, others had few difficulties. In the future, perhaps a larger population of survivors of central nervous system malignancies would reveal more difficulties with the course load required to enter the medical profession.

When reviewing the responses of the survivors, it was with regret that the authors found some of their dreams had fallen short. Unfortunately, even after treatment, the experience of childhood cancer follows a survivor for many years, and one can see that the experience does impair the ability of some survivors to achieve goals set before the cancer diagnosis

Many survivors focused on their peer relationships when responding to the open-ended questions. The authors of the study anticipated responses about educational difficulties when including the question about how difficult it was for survivors to return to school after treatment. However, the survivors focused more on their peer relationships and the social factor of returning to school after an extended absence. The authors of the study noted that socialization and maturation are important in adolescents, and believe that these factors influenced the survivors' perceptions of the difficulties of returning to school.

Finally, the survivors expressed a positive outlook on life despite a challenging period of time. Many clinicians describe the resilience they experience from children encountered, and the expressions of positivity are an example of this resilience (Chin-Mi et al., 2014).

Discussion

The findings of this mixed-methods survey study, despite the low response, indicated that survivors with CNS tumors may have visual impairment; however, it does not appear this impairment affected educational outcomes in this small population. CNS tumor survivors were the same group who reported tinnitus, problems with balance, and problems with double vision. They also reported receiving CNS radiation at some point during their treatment. The findings of visual impairment are consistent with the 2010 findings of Whalen et al. These impairments, while significant to the survivors, do not appear to be significant in their effect on the later educational or employment outcomes in this admittedly small population.

Surprisingly, there were no statistically significant findings between CNS tumor survivors and educational and employment outcomes. Kirchoff et al. (2011) suggested that survivors of CNS tumors would experience cognitive difficulties related to their tumor and treatment that would later impact their ability to be employed. The investigators of the study hypothesized that more school missed would correlate with worse educational and career outcomes post treatment. It appears though that survivors who reported a large amount of missed school were the same survivors who experienced homebound education. Survivors who reported homebound schooling saw that as having missed school. The difference was in the socialization they missed by attending school, as indicated in the qualitative findings.

Responses to qualitative questions revealed a polarization surrounding the later wishes of survivors to be involved in the medical field. While some survivors reported that the experience inspired them to choose a profession related to medicine or hospitals, others reported a desire to never enter a hospital again. The authors of the study hypothesized that strong utilization of support resources would correlate with a desire for a profession in the medical field, but no statistically significant findings existed on this topic.

Limitations

This study had several limitations warranting discussion. First it was a single institution study with a small sample size. The sample size was impacted because of the inability to contact survivors individually to hopefully enhance recruitment due to the anonymity of this survey, and would have offered investigators the opportunity to conduct follow up phone calls to survivors after the mailed survey was completed. This study also

did not contain a control group, whereas many studies utilizing the CCSS questionnaire also study healthy siblings for comparison.

Implications for Future Study

In the future, a larger sample of CNS tumor survivors would be helpful to try and determine how the side effects of CNS tumor treatment affect later educational and employment outcomes. Ways to enhance sample size would include the utilization of collaborating institutions and an online response system. While the introduction of an online response system requires much effort to ensure confidentiality, the increasing dependence on electronic devices in the younger generations could increase their response rate.

Nursing Implications

Nursing implications from this study surround the socialization of patients. Adolescents on treatment yearn for the socialization they had before treatment, and experience losses from the inability to attend schooling. Nurses should support their patients and encourage visits from friends and activities outside of the home as health permits, in order to keep life for patients on treatment as normal as possible.

Conclusion

Survivors of cancer are affected physically, emotionally, and socially. While specific diagnosis can predict long term physical effects, survivors in general have commonalities in the social and emotional realms. Support on treatment can help mitigate these long term issues, and assist the survivor in transitioning from active treatment to long term follow up.

APPENDIX A: DEMOGRAPHIC DATA FORM

Respondents responded to the following:

- Current Age
- Age at Diagnosis
- Years off Cancer Therapy
- Gender
- Radiation therapy (yes/no)
- Radiation therapy to head or brain (yes/no)
- Chemotherapy (yes/no)
- Spinal chemotherapy (yes/no)
- School days missed (estimated) during and after therapy
- Special education used before treatment (yes/no)
- Special education used after treatment (yes/no)
- Diagnosis (leukemia/lymphoma/non-hodgkins lymphoma/neuroblastoma/wilm's tumor/bone tumors/CNS tumor/soft tissue sarcoma/retinoblastoma/melanoma/other)

APPENDIX B: CCSS QUESTIONNAIRE

A5. To which of the following groups do you belong?

- White
- Black
- American Indian or Alaskan Native
- Asian
- Pacific Islander
- Other (specify)

B7. At the present time, do you have any of the following (check yes or no)

- Persistent hair loss
- Scarring or disfigurement of the head or neck region (including the face)
- Scarring or disfigurement of the arms or legs (including an abnormally short arm or leg)
- Walk with a limp
- Loss of an arm or a leg
- Loss of an eye
- Other (specify)

Have you ever been told by a doctor or other health care professional that you have, or have had... (answers no, yes and the condition is still present, yes but the condition is no longer present, not sure; add age of first occurrence)

- C1. Hearing loss requiring a hearing aid
- C2. Deafness in both ears not completely corrected by hearing aid
- C3. Deafness in only one ear not completely corrected by hearing aid
- C4. Tinnitus or ringing in the ears
- C5. Persistent dizziness or vertigo
- C6. Hearing loss, not requiring a hearing aid
- C7. Any other hearing problems, specify
- C9. Legally blind in both eyes (if yes, any sight)
- C10. Cataracts
- C11. Glaucoma (excess pressure in the eyeball)
- C12. Problems with double vision
- C13. A detached retina or any other condition of retina (if yes, describe)
- C14. Crossed or turned eyes (strabismus)
- C15. Lazy eye (amblyopia)
- C16. Any other trouble seeing with one or both eyes even when wearing glasses
- C17. Very dry eyes requiring eye drops or ointment
- C18. Any other eye problems (if yes, describe)
- C19. Stammering or stuttering
- C20. Any other speech defects (if yes, describe)
- C21. Abnormal sense of taste
- C22. Loss of taste or smell lasting for 3 months or more?
- J1. Problems with learning or memory (specify mild, moderate, severe, disabling)

J2. Epilepsy, repeated seizures, convulsions, or blackouts (describe and answer if on medication)

J3. Migraine

J4. Other severe headaches (if yes, list medications to control)

J5. Problems with balance, equilibrium, or ability to reach for or manipulate objects (specify mild, moderate, severe, disabling)

J6. Tremors or problems with movements

J7. Problems chewing or swallowing solids or liquids

J8. Decreased sense of touch or feeling in hands, fingers, arms or legs

J9. Prolonged pain in arms, legs, or back

J10. Abnormal sensation in arms, legs or back

J11. Weakness or inability to move arms

Please indicate if you have ever had any of the following surgical procedures done (no, yes, not sure, age)

I1. Amputation of arm, leg, hand, foot (if yes, specify)

I2. Scoliosis surgery (insertion of rods or other methods to straighten the spine)

I3. Other surgery of spinal cord or spine (if yes, specify)

I4. Leg lengthening or shortening procedures

I5. Joint replacement (if yes, specify)

I6. Other bone surgery (if yes, specify)

I7. Coronary artery bypass surgery

I8. Pericardectomy (stripping of the sac around the heart)

I29. Bone marrow transplant

R1. What is the highest grade or level of schooling that you have completed?

1-8 years (grade school)

9-12 years (high school, but did not graduate)

Completed high school/GED

Training after high school, other than college

Some college

College graduate

Post graduate level

Other (specify)

R2. If you have completed high school, did you receive a regular high school diploma or did you received a high school equivalency certificate, also called a GED?

R3. In elementary, junior, or high school were you ever in any of the following programs? (Mark all that apply) (No, Yes, not sure)

Learning disabled or special education program (If yes, were you in the program because of missed school, low scores on tests, problems learning or concentrating, emotional or behavioral problems)

Advanced placement or talented program

Homebound education for at least one school year

R4. If you were in a learning disabled or special education program, what grades were you in at that time, mark all that apply.

S1. Have you ever had a job

S2. What is your current employment status? Include unpaid work in the family business or farm, mark all that apply.

Not currently working

Working full time (30 or more hours per week)

Working part time (less than 30 hours per week)

Caring for home or family (not seeking paid work)

Unemployed and looking for work

Unable to work due to illness or disability

Retired

Student

Other, specify

S3. The following questions are about your present occupation. Please write your job title and brief details of what you do. If you have more than one job, please give the title of your main job (please give only one)

S3a. Main job title

S3b. Please briefly describe your primary job tasks

S4. Have you ever applied for entry into the following services (no, yes)

Military (Army, Navy, etc)

Police department

Fire department

S5. Have you ever not gotten a job or into military service because of your previous medical history

Civilian job

Military (Army, Navy, etc)

Police department

Fire department

APPENDIX C: QUALITATIVE QUESTIONS

1. Before you were diagnosed with cancer, tell me what you wanted to be when you grew up.
2. What was it like going back to school after diagnosis or after you were done with cancer treatment?
3. How did your having cancer change what you wanted to be when you grew up?
4. If you have any late effects of your cancer treatment like amputations, vision/hearing problems, learning problems, how are they affecting your ability to be successful with your education/career goals?
5. Did you use any of the following resources at [hospital name] to help you make your education or job decisions?
 1. Answer options included written information, nurse educator, nurse, nurse practitioner, social worker, [hospital name] teachers, doctor, or other.
6. If the answer to question five was yes, were they helpful?
7. Anything else you would like to share?

TABLE 1: DEMOGRAPHICS OF POPULATION

Characteristic	N(%)	Mean (Range)
Gender		
Male	29 (62%)	
Female	18 (38%)	
Current Age Range		27.4 (18-43)
Age Range at Diagnosis		13.9 (12-1)
Radiation Therapy?		
Yes	18 (38%)	
No	29 (62%)	
Radiation to the CNS?		
Yes	10 (21%)	
No	37 (79%)	
Chemotherapy?		
Yes	46 (99%)	
No	1 (1%)	
Chemotherapy to the CNS?		
Yes	18 (38%)	
No	29 (62%)	
Estimated School Days Missed on Therapy		105.4 (0-360)
Estimated School Days Missed after Therapy		19 (0-180)
Special Education Utilized Before Therapy		
Yes	11 (23%)	
No	36 (77%)	
Special Education Utilized After Therapy		
Yes	16 (34%)	
No	31 (66%)	

Characteristic	N (%)
Diagnosis	
Acute Lymphoblastic Leukemia	15 (32%)
Hodgkin's Lymphoma	5 (11%)
Non-Hodgkin's Lymphoma	12 (26%)
Bone cancer	5 (11%)
Central Nervous System Tumor	4 (9%)
Soft Tissue Sarcoma	1 (1%)
Skin	1 (1%)
Other	4 (9%)
Ethnicity	
White	39 (83%)
African American	2 (4%)
Other	6 (13%)

REFERENCES

- Barton, S. E., Najita, J. S., Ginsburg, E. S., Leisenring, W. M., Stovall, M., Weathers, R. E., & ... Diller, L. (2013). Infertility, infertility treatment, and achievement of pregnancy in female survivors of childhood cancer: a report from the Childhood Cancer Survivor Study cohort. *Lancet Oncology*, *14* (9), 873-881. doi:10.1016/S1470-2045(13)70251-1
- Brinkman, T., Ullrich, N., Zhang, N., Green, D., Zeltzer, L., Lommel, K., & ... Krull, K. (2013). Prevalence and predictors of prescription psychoactive medication use in adult survivors of childhood cancer: a report from the Childhood Cancer Survivor Study. *Journal Of Cancer Survivorship*, *7* (1), 104-114. doi:10.1007/s11764-012-0250-x
- Chin-Mi, C., Yueh-Chih, C., & Tai-Tong, W. (2014). Comparison of Resilience in Adolescent Survivors of Brain Tumors and Healthy Adolescents. *Cancer Nursing*, *37* (5), 373-381. doi:10.1097/NCC.0000000000000094
- Gurney, J. G., Ness, K. K., Sibley, S. D., O'Leary, M., Dengel, D. R., Lee, J. M., & ... Baker, K. S. (2006). Metabolic syndrome and growth hormone deficiency in adult survivors of childhood acute lymphoblastic leukemia. *Cancer*, *107* (6), 1303-1312.
- Henderson T, Whitton J, Diller L, et al. Secondary sarcomas in childhood cancer survivors: a report from the Childhood Cancer Survivor Study. *JNCI: Journal of The National Cancer Institute* [serial online]. February 21, 2007; 99 (4):300-308. Available from: CINAHL Complete, Ipswich, MA. Accessed November 25, 2014.

- Jose, R., & Sujatha, R. (2012). A Comparative Study on Emotional Maturity among Adolescent Boys and Girls. *International Journal of Nursing Education*, 4 (2), 73-76.
- Kirchhoff, Anne C & Krull, Kevin R & Ness, Kirsten K & Armstrong, Gregory T & Park, Elyse R & Stovall, Marilyn & Robison, Leslie L & Leisenring, Wendy. (2011). Physical, mental, and neurocognitive status and employment outcomes in the childhood cancer survivor study cohort. *Cancer epidemiology, biomarkers & prevention: a publication of the American Association for Cancer Research, co-sponsored by the American Society of Preventive Oncology*, 20. Retrieved from <http://www.biomedsearch.com/nih/Physical-Mental-Neurocognitive-Status-Employment/21844244.html>
- Lansdale, M., Castellino, S., Marina, N., Goodman, P., Hudson, M. M., Mertens, A. C., &... Oeffinger, K. C. (2010). Knowledge of hepatitis C virus screening in long-term pediatric cancer survivors: a report from the Childhood Cancer Survivor Study. *Cancer*, 116 (4), 974-982. doi:10.1002/cncr.24810
- Mertens, A., Brand, S., Ness, K., Li, Z., Mitby, P., Riley, A., & ... Zeltzer, L. (2014). Health and well-being in adolescent survivors of early childhood cancer: a report from the Childhood Cancer Survivor Study. *Psycho-Oncology*, 23 (3), 266-275. doi:10.1002/pon.3414
- Mertens, A., Yasui, Y., Neglia, J., Potter, J., Nesbit, M. J., Ruccione, K., & ... Robison, L. (2001). Late mortality experience in five-year survivors of childhood and

adolescent cancer: the Childhood Cancer Survivor Study. *Journal of Clinical Oncology*, 19 (13), 3163-3172.

Mitby, Pauline A., Robison, L. L & Whitton, John A & Zevon, Michael A & Gibbs, Iris C & Tersak, Jean M & Meadows, Anna T & Stovall, Marilyn & Zeltzer, Lonnie K & Mertens, Ann C & . (2003). Utilization of special education services and educational attainment among long-term survivors of childhood cancer: a report from the Childhood Cancer Survivor Study. *Cancer*, 97. Retrieved from <http://www.biomedsearch.com/nih/Utilization-special-education-services-education/12569614.html>

Mulrooney, D., Yeazel, M., Kawashima, T., Mertens, A., Mitby, P., Stovall, M., & ... Leisenring, W. (2010). Cardiac outcomes in a cohort of adult survivors of childhood and adolescent cancer: retrospective analysis of the Childhood Cancer Survivor Study cohort. *BMJ: British Medical Journal (Overseas & Retired Doctors Edition)* doi:10.1136/bmj.b4606

Nagarajan, Rajaram & Neglia, Joseph P & Clohisy, Denis R & Yasui, Yutaka & Greenberg, Mark & Hudson, Melissa & Zevon, Michael A & Tersak, Jean M & Ablin, Arthur & Robison, Leslie L. (2003). Education, employment, insurance, and marital status among 694 survivors of pediatric lower extremity bone tumors: a report from the childhood cancer survivor study. *Cancer*, 97 (10), 2554-2564.

Ries LAG, Smith MA, Gurney JG, Linet M, Tamra T, Young JL, Bunin GR (eds). *Cancer Incidence and Survival among Children and Adolescents: United States SEER Program 1975-1995*, National Cancer Institute, SEER Program. NIH Pub .No.99-4649. Bethesda, MD,1999

- Steele, J., Wall, M., Salkowski, N., Mitby, P., Kawashima, T., Yeazel, M., & ... Mertens, A. (2013). Predictors of risk-based medical follow-up: a report from the childhood cancer survivor study. *Journal of Cancer Survivorship*, 7 (3), 379-391. doi:10.1007/s11764-013-0280-z
- Whelan, K. F., Stratton, K., Kawashima, T., Waterbor, J. W., Castleberry, R. P., Stovall, M., & ... Mertens, A. C. (2010). Ocular late effects in childhood and adolescent cancer survivors: a report from the childhood cancer survivor study. *Pediatric Blood & Cancer*, 54 (1), 103-109. doi:10.1002/pbc.22277
- Williamson, H. (2014). The psychosocial impact of being a young person with an unusual appearance. *Journal of Aesthetic Nursing*, 3 (4), 186-188.
- Zebrack, B. J., Zeltzer, L. K., Whitton, J., Mertens, A. C., Odom, L., Berkow, R., & Robison, L. L. (2002). Psychological outcomes in long-term survivors of childhood leukemia, Hodgkin's disease, and non-Hodgkin's lymphoma: a report from the Childhood Cancer Survivor Study. *Pediatrics*, 110 (1), 42-52.
- Zeltzer, L. K., Lu, Q., Leisenring, W., Tsao, J. I., Recklitis, C., Armstrong, G., & ... Ness, K. K. (2008). Psychosocial outcomes and health-related quality of life in adult childhood cancer survivors: a report from the childhood cancer survivor study. *Cancer Epidemiology, Biomarkers & Prevention: A Publication of The American Association For Cancer Research, Cosponsored By The American Society Of Preventive Oncology*, 17 (2), 435-446. doi:10.1158/1055-9965.EPI-07-2541