2018

Developmental Outcomes of Pediatric Cancer Survivors After Chemotherapy

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Developmental Outcomes of Pediatric Cancer Survivors After Chemotherapy

An Honors Thesis submitted in partial fulfillment of the requirements for Honors in School of Nursing.

By
Kaley Scanlon

Under the mentorship of Dr. Crystal Edds-McAfee

ABSTRACT
PURPOSE: With the increased survival rates in pediatric cancer, these patients are exhibiting new possible long-term side effects, such as delays in cognitive and social-emotional development. The purpose of this research study is to assess the cognitive and social-emotional developmental outcomes of pediatric cancer survivors who currently receive chemotherapy or have received chemotherapy in the past.

DESIGN/METHODS: This pilot study used a quantitative survey to assess cognitive and social-emotional developmental outcomes of pediatric cancer survivors. The inclusion criteria for this study included parents of school aged children (ages 5-18) who received chemotherapy for at least six months, either currently or in the past. The data collected from the surveys was coded and analyzed through the IBM Statistical Package for Social Sciences (SPSS) for significance.

RESULTS: Five participants were recruited either from a hematology and oncology clinic or a cancer survivorship group to fill out the survey. The results of this study were that there is most likely a difference in the developmental effects for patients who are currently receiving chemotherapy compared to those in remission who have previously received chemotherapy.

CONCLUSIONS: These results indicate that that pediatric cancer survivors experience cognitive and social-emotional developmental effects, which may vary based on if the child is still receiving treatment or is in remission. As the number of pediatric cancer survivors increases, it is essential for healthcare professionals to understand and be aware of possible cognitive and social-emotional developmental changes related to chemotherapy.

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April 2018
School of Nursing
University Honors Program
Georgia Southern University
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Acknowledgments

I would like to thank the Georgia Southern University Honors Program for providing me the opportunity to conduct undergraduate research. In addition, I would like to thank the faculty and staff of the University Honors Program, especially Dr. Engel, Dr. Desiderio, and Erin Martin, for their assistance and guidance which ensured my academic success throughout my time in the Honors program.

In addition, I would like to thank the Georgia Southern University School of Nursing, especially Dr. Melissa Garno, who serves as the School of Nursing Honors Coordinator. Thank you to all of my professors who assisted with my projects and research. Most importantly, thank you to my honors advisor Dr. Crystal Edds-McAfee whose support, guidance, and encouragement made this entire project possible.

I also would like to thank Traci Marsh from the Memorial Health University Medical Center pediatric hematology/oncology clinic, as well as, Amada Crosby from the cancer survivorship group who assisted me in survey collection.

Finally, I would like to thank my family and friends for their love and encouragement throughout my entire undergraduate academic career. Many of my academic accomplishments, including this project, would have not been possible without their constant support.
Developmental Outcomes of Pediatric Cancer Survivors After Chemotherapy

Due to recent advances in treatments, pediatric cancer patients have an increased survival rate associated with the implementation of various treatment measures (Li, Lopez, Chung, Ho, & Chiu, 2013). On average, there are over 375,000 pediatric cancer survivors in the United States, a number that has increased in the last forty years, which is commonly attributed to implementation of many different treatment methods, including chemotherapy (Ward et al., 2014). Implementation of chemotherapy to slow or stop growth of body cells, predominantly cancer cells, is a widely used form of treatment that has increased the survivorship of patients with childhood cancer when combined with an early diagnosis (Ward, DeSantis, Robbins, Kohler, & Jemal, 2014). The benefits from improved treatment measures is evident in the increasing survival rate, however, pediatric cancer survivors now face a higher risk of serious health conditions or developmental delays that have both chronic and late effects on the survivors (Miller et al., 2016). This research study will quantitatively assess the developmental outcomes of pediatric cancer survivors who currently receive chemotherapy or have received chemotherapy in the past. The developmental outcomes assessed in this study include cognitive and social-emotional development, in order to investigate what deficits or delays may exist for these patients.

**Background**

The short-term impacts of chemotherapy during treatment often receive more attention in the research, while the long-term impacts of chemotherapy on pediatric cancer survivors is commonly underexplored within the research (Li et al., 2013). For pediatric cancer survivors, a cure comes at a cost, with increased risk and incidence of
cognitive or social-emotional developmental delays, months and even years after their chemotherapy treatment has ended (Li et al., 2013). Previous research often evaluates cognitive and social-emotional developmental outcomes separately when looking at chemotherapy treatment effects on pediatric cancer patients or survivors. Through looking at the topics related to these developmental outcomes within the research, a broader understanding can be gained on what factors could possibly play a role in changing these developmental outcomes including the start, duration, and intensity of chemotherapy treatment.

**Cognitive Development**

One-third of pediatric cancer survivors suffer from cognitive impairments, often due to chemotherapy treatment (Miller et al., 2016). Cognitive development deficits due to chemotherapy treatment can consist of different neurocognitive impairments, with diverse severity based on risk factors, such as a younger age at diagnosis (Buizer, de Sonneville, & Veerman, 2009). Younger children have less mature brain structures and a smaller amount of white matter, increasing their vulnerability to the neurotoxic effects of chemotherapy (Buizer et al., 2009). The most common long-term cognitive deficits found in pediatric cancer survivors receiving chemotherapy treatment, include alterations in attention and executive functioning (Buizer et al., 2009). Other cognitive developmental changes include altered or decreased processing speed, working memory, and visual spatial abilities (Lewis, Perry, & Murdoch, 2013). Other factors influenced by chemotherapy treatment that should be considered when looking at cognitive development, include both visual and hearing impairments (Ward et al., 2014). Additionally, pediatric cancer survivors who underwent chemotherapy treatment are
often found to have reduced language outcomes, vocabulary and grammar deficits, and reduction in naming abilities (Lewis et al., 2013).

For pediatric cancer survivors treated with chemotherapy, the long term cognitive deficits can also impact other aspects of their daily life. The various cognitive development deficits seen in survivors treated with chemotherapy often have a impact on intellectual and academic functioning (Raymond-Speden, Tripp, Lawarence, & Holdaway, 2000). Academic problems are evident from parent and teacher reports of survivors’ school performance, as well as, standardized test scores (Raymond-Speden et al., 2000). In addition, pediatric cancer survivors who were treated with chemotherapy have increased behavioral difficulties (Anderson, Godber, Smitber, Weiskop, & Ekert, 2000). Long-term effects of chemotherapy on the cognitive state of pediatric cancer survivors may continue into adulthood, impacting quality of life, functional status, and behavioral adjustments (Moore, Hockenberry, & Krull, 2013). This shows the importance of early interventions to correct preventable developmental changes due to chemotherapy, and the importance of also analyzing social-emotional developmental in the provision of holistic care for pediatric cancer survivors.

Social-Emotional Development

As the survival rates of pediatric cancer patients has increased, social-emotional development has become more of a priority, with a focus on the need for adequate health-related quality of life for survivors. Health-related quality of life is a multidimensional concept that looks at “psychological functioning, physical state, social function, and capacity of performing activities of daily living” (Pemberger et al., 2005, p. 50). Similar to other developmental domains, social-emotional developmental deficits can have both
chronic and late effects, lasting years after the initial diagnosis and chemotherapy treatment (Pemberger et al., 2005). Pediatric cancer survivors treated with chemotherapy were commonly found to have lower health-related quality of life scores than healthy population controls of the same age and gender (Speechley, Barrera, Shaw, Morrison, & Manusell, 2006). For many survivors of childhood cancer, numerous factors influenced the differences in health-related quality of life scores, including the survivor’s age at diagnosis, cancer type, as well as, the type of treatment (Speechley et al., 2006). Additional issues that pediatric cancer survivors face that influence the overall health-related quality of life, include health care utilization or availability, behavior problems, psychological issues, any second malignancies, late mortality, and socioeconomic status (Cantrell, 2011). Health-related quality of life is only one aspect of social-emotional development that highlights the numerous effects chemotherapy treatment can have on survivors.

Beyond health-related quality of life, pediatric cancer survivors treated with chemotherapy have been found to have negative emotional developmental outcomes, as well as, an increased risk of maladjustment when returning to normal activities (Cantrell, 2011). When looking at the lasting impact of chemotherapy, survivors have been found to have an increased risk of depression and somatic distress due to psychologically stressful events during treatment and remission (Zebrack et al., 2002). In addition, pediatric cancer survivors have lower levels of self-esteem and increased levels of uncertainty and fear due to the possibility of second malignancies, when compared to their peers (Li et al., 2013). Another major developmental change due to chemotherapy that survivors may face is social disruption or isolation (Li et al., 2013). Chemotherapy treatment decreases
the survivors’ immune response and increases their risk of infection, which leads to an alteration in their social patterns, such as frequent avoidance of crowded public places (Li et al., 2013). The shift in pediatric cancer survivors’ social interactions contributes to disrupted relationships and the feeling of being left out, which negatively impacts their social-emotional development (Li et al., 2013). In contrast to predominately negative social-emotional developmental outcomes, pediatric cancer survivors can have some positive developmental outcomes in response to their chemotherapy treatment. For example, many pediatric survivors developed a closer relationship with their family and became more mature, with a better ability to handle various problems after chemotherapy treatment (Yallop, McDowell, Koziol-McLain, & Reed, 2013).

**Significance of Study**

When dealing with pediatric cancer, health care professionals, parents and patients have to sometimes make difficult decisions between effective treatment measures, such as chemotherapy, and the possible long-term developmental effects. It is evident that the increased survival rate of pediatric cancer patients is attributed to medical advances in the field, including the improvement of treatment methods like chemotherapy. Developmental deficits and changes because of chemotherapy treatment is evident in all domains of development, including cognitive development and social-emotional development. It is essential that health care professionals, such as nurses, are aware of these developmental changes that can occur in pediatric cancer survivors who were treated with chemotherapy. This awareness allows for early identification of any potential problems. Currently, there is a lack of research that discusses the general developmental delays or deficits pediatric cancer survivors may face, especially a few
years after remission. Also, there is a lack of research that compares the developmental outcomes of pediatric cancer survivors based on the age they received cancer treatment. Therefore, the implications of this study would be to begin to assess and identify commonalities in the cognitive and social-emotional developmental outcomes for pediatric cancer patients and survivors who have received chemotherapy.

**Purpose**

When looking at the purpose of this study, it is to evaluate the developmental outcomes of pediatric cancer patients who currently receive chemotherapy or have received chemotherapy in the past. It is intended that the findings from this study could contribute to the existing research, and prompt future investigation of the developmental outcomes of pediatric cancer survivors. This study also aims to identify if differences exist in cognitive and social-emotional developmental outcomes between pediatric cancer survivors, depending on the age they received chemotherapy treatment. The research questions addressed are (1) What are the long term cognitive and social-emotional development effects on pediatric cancer patients who received chemotherapy? (2) Is there a difference in the developmental outcomes for survivors, based on the age the receive cancer treatment? (3) Is there a difference in developmental effects for patients who are currently receiving chemotherapy compared to those in remission who previously received chemotherapy? It is hypothesized that every age group of pediatric cancer survivors will experience developmental delays or deficits in both cognitive and social-emotional development. However, it is also hypothesized that there will be a difference in the developmental outcomes for survivors, based on what age they began receiving treatment. In addition, it is hypothesized that there will be a difference in the cognitive
and social-emotional development between patients who are currently still receiving treatment compared to those who have received treatment in the past.

**Method**

In this pilot study, the developmental outcomes were investigated for pediatric cancer patients who currently receive chemotherapy and survivors who have received chemotherapy in the past. Before beginning this study, the researcher obtained approval from the Georgia Southern University Institutional Review Board. Participants were recruited from the Pediatric Hematology and Oncology clinic at Memorial Health University Medical Center, as well as, from a cancer survivorship group. The participants of this study were parents of children that were school age (ages 5-18) and received chemotherapy for at least six months, either currently or in the past. The inclusion criteria for the parent or guardian to participate in the study was to be at least 18 years of age, have legal guardianship of the child, and know the child’s history. On select days questionnaires and informed consents were handed out in person to parents or guardians who had children that met the inclusion criteria. The questionnaire contained demographic information, information about the child’s cancer diagnosis and treatment, as well as, questions about the cognitive and social-emotional changes seen in the child (see Appendix B for questionnaire). Once the questionnaires were filled out, the parents or guardians returned surveys to the investigator. Questionnaires were then coded with no identifying information on them. The consents and questionnaires will be stored in separate locked boxes at Georgia Southern University School of Nursing, for three years of archival. Then after three years the surveys and informed consents will be destroyed. Data collected from the questionnaires was analyzed through IBM Statistical Package for
the Social Sciences (SPSS) software, to organize and interpret findings through descriptive statistics.

Data Analysis and Results

Five caregivers were recruited from an outpatient hematology and oncology clinic or a cancer survivorship group to participate in this study. Only one participant had a child who identified as “other race,” while the remaining children were reported as Caucasian (80%). Four of the five selected participants (80%) had daughters who were 13-18 years of age and either currently receive or have previously received chemotherapy. In addition, the diagnosed female patients were 13-18 years old. The cancer diagnoses reported for the diagnosed females included “Acute Myeloid Leukemia (AML),” “Acute Lymphoblastic Leukemia (ALL),” and “Leukemia.” The only diagnosed male included in this study was in the 6-8 age group and had a diagnosis of “Stage IV high-risk neuroblastoma.” Two children were diagnosed between the ages of 3-5 years (40%), while the remaining children were diagnosed at 0-2 years (20%), 9-12 years (20%), and 16-18 years (20%). Also, two children were treated with chemotherapy alone, while the remaining children had additional forms of cancer treatment including bone marrow transplants, surgery, radiation, or immunotherapy. For the children included in this study, two have been in remission for more than 10 years, one has been in remission for 0-3 years, and two are still receiving treatment.

During this study, the data was analyzed through IBM SPSS software to determine the results. When looking at the results, there were some similarities between all of the children regardless of age of diagnosis, length of treatment, or remission status. There was no indication of any speech problems for any of the children in this study,
since no issues were reported by parents on the questionnaire. Also, three children exhibited being “overtired without good reason” and “sleeping more than most kids during day or night” some of the time. In the short answer portion of the questionnaire, four out of five parents reported that their child was involved in at least two activities, sports, or hobbies. One parent did not fill in this question, so it is not known if that child participates in any activities. Some of the activities the children participate in include “volunteering, reading, art, cooking, walking, basketball, make-up, and working out.”

When asked “compared to other children of similar age, my child’s behavior is different because of problems experienced during remission/treatment,” one parent strongly disagreed (20%), three parents disagreed (60%), and one parent neither agreed nor disagreed (20%). Also, when looking at how the child gets along with siblings, other kids, and parents, the parents reported their children to be average (60%) or better than average (40%) when interacting with these groups. Specifically looking at the number of friends (not including siblings), parents reported their child having “2 or 3 friends” (60%) or “4 or more friends” (40%). Three of the children spend time with friends outside of school less than once a week, and two spend time with friends outside of school once or twice a week. Parents denied that their children break any rules at home, school or elsewhere. Also, the parents reported that none of the children receive special education/remediation services, have academic problems, or have behavioral problems at school. School performance was reported as average or above average, in reading and history for the all children. However, one child (20%) fell below average in math and two children (40%) were below average in science.
From the children included in this study, two (40%) received treatment for 0-12 months, and three (60%) received treatment for 1-3 years. The parents of the children treated for 1-3 years reported more issues than those treated for 0-12 months. Of the issues reported, 66% of those treated for 1-3 years reported that their children “impulsively act without thinking,” “are inattentive or easily distracted,” and “feel that he/she has to be perfect” sometimes or often. The remaining parents who had children receiving treatment for 0-12 months reported that these things were not true for their child. In addition, 66% of children treated for 1-3 years were reported as being “withdrawn, doesn’t given involved with others” along with “doesn’t get along with other kids” some of the time. However, there was little to no correlation between the length of treatment and the child’s academic performance or behavior for all participants.

Similar to length of treatment, there were a few responses that were affected by the child’s age of diagnosis. One child was diagnosed between 0-2 years, two children were diagnosed between 3-5 years, one child was diagnosed between 9-12 years, and one child was diagnosed between 16-18 years. Some of the results seemed to be age dependent where they only effected either the older children (9-12 years and 16-18 years) or the younger children (0-2 years and 3-5 years). All of the parents of the older children (>9 years) reported that their child sometimes or often experiences difficulty with “sitting still, being restless or hyperactive,” while none of the parents of the younger children reported this. In contrast, 66% of younger children were reported by their parents to often “not get along with other kids,” where the parents of the older children reported not true.

From parent reports, it was determined that 40% of the children were currently still receiving treatment/not in remission, 20% were in remission for 0-3 years, and 40%
were in remission for more than 10 years (see Appendix A: Table 1). When analyzing the results, the children were divided into those who were still receiving treatment and those in remission (0-3 years and more than 10 years). A cross-tabulation showed that all parents with children in remission reported that their child occasionally finds little he/she enjoys and are overtired without good reason. However, those still receiving treatment did not report these experiences. In addition, parents reported sometimes true for children in remission for 0-3 years and often true for children in remission for more than 10 years when asked if their child does not get along with other kids and would rather be alone than with others. Of the children in remission, parents reported that these children were sometimes “too shy or timid” and that 66% were sometimes or often “inattentive or easily distracted.” When asked if their child was “limited in schoolwork and activities” and “limited in the amount of time spent with friends,” parents with children currently in treatment reported agree or strongly agree to the statements, while parents with children in remission strongly disagreed or disagreed with the statements. The child in remission for 0-3 years was reported to sometimes “act too young for his/her age” and “feel worthless and inferior.” Also, the children in remission for 0-3 years and those still in treatment were reported to sometimes experience difficulty with “failing to finish things that he/she starts,” and sitting still, whereas those in remission for more than 10 years did not report difficulty with these things.

**Discussion and Implications of Findings**

The results of this study indicate that children who have been treated with chemotherapy, do not have significant academic or behavioral problems in school, and do not require special education/remediation services. The impact of chemotherapy on these
children is not as severe as previous research has indicated. However, it is still evident from the results that developmental problems continue to exist, but in a more minor way that could ideally be managed by the children and their families. Also, the results highlighted that children treated with chemotherapy have minimal behavior issues reported, which could suggest that these children experience other types of changes in their development after treatment.

In addition, this study had an increased frequency of changes in social-emotional development than cognitive development after chemotherapy treatment. Social-emotional developmental outcomes include the child’s interaction with others, behavior changes such restlessness and irritability, as well as, the feeling of worthlessness and inability to finish tasks. The results of this study did include changes in both cognitive and social-emotional development, which indicates that both can be affected by chemotherapy treatment. However, further research is needed to distinguish if one domain of development has more complications than the other. In order to further address the proposed research questions, the data was analyzed through cross-tabulations to evaluate if the length of treatment, age of diagnosis, or remission status could be factors that influenced the results.

**Length of Treatment**

When looking at the cross-tabulations, the length of treatment seemed to have an impact on some responses suggesting that increased chemotherapy exposure may have a greater impact on a child’s development. This is seen from the reports that children treated for 1-3 years tended to have more frequent issues than those treated from 0-12 months. For example, children treated for 1-3 years were reported to sometimes or often
be inattentive or easily distracted, as well as, more likely to not get along with other kids. In this study, the child’s social-emotional development, such as interaction with others, impulsivity, and desire to be perfect, were more often impacted by the length of treatment.

**Age of Diagnosis**

The smaller sample size in this pilot study was primarily due to a lack of access to pediatric cancer patients or survivors that met the inclusion criteria of school age children (5-18 years) who have received chemotherapy for at least six months. This could have possibly influenced the lack of significance in the cross-tabulations between the age of diagnosis and developmental outcomes. There was some indication that the younger or older the child was at the age of diagnosis could possibly impact some developmental outcomes, but these trends were not consistent throughout the research. For this study, it can be concluded that the age of diagnosis did not impact the developmental outcomes for pediatric cancer survivors. While the age of diagnosis did not impact the developmental outcomes in this pilot study, a larger sample size could produce different trends and/or results.

**Remission Status**

Cross-tabulations revealed trends between children who are currently still receiving chemotherapy and children who previously received treatment. There were differences in the changes in cognitive and social development for those currently receiving treatment versus those in remission. This indicates that the problems or complications pediatric cancer survivors or patients experience can start, disappear, or
change as the individual transitions from treatment to remission. Since remission is the goal for the majority of pediatric cancer patients, it is essential to know what variables to be aware of in order to ensure the best care is provided for this patient population to ensure the greatest quality of life. However, it is also important to assess whether other factors could be influencing these results, such as the weakened immune system and fatigue experienced by patients still receiving treatment. In addition, there are also specific differences in variables for survivors based on the number of years they have been in remission. There were not enough participants to represent each stage of remission in this study, however, a comparison was made among the children in early remission (0-3 years) and survivorship (>10 years). The comparison revealed that the early remission children exhibited immaturity and lower self-esteem, while those in the later stages of survivorship had difficulty with focusing and excessive hyperactivity.

Even more specifically, out of the five children in this study four were 13-18 years old females, diagnosed with a form of leukemia. By eliminating other possible factors that could influence questionnaire responses such as type of cancer, age, and gender, the female group provided insight on how developmental outcomes could be different for those in treatment compared to those in remission. Children in early remission (0-3 years) were reported to sometimes have difficulty getting along with other kids or being too shy, while children in later remission (more than 10 years) reported these to occur more often (see Appendix A: Table 2). For children still receiving treatment they were reported to have difficulty finishing things he/she starts and being confused or in a fog (see Appendix A: Table 2). These differences could be explained by the fact that the impacts on a child’s development from chemotherapy may be drastically
different while the child is actively receiving the drug compared to having previously been given the drug and instead dealing with the residual effects of chemotherapy. Through these results, it can be concluded that there is most likely a difference in the developmental outcomes between patients who are currently receiving chemotherapy and those in remission who have previously received chemotherapy.

**Recommendations**

This research study revealed long term effects on cognitive and social-emotional developmental that can differ based on if the patient is currently receiving chemotherapy treatment or is in remission. The results from this study can be implemented to enhance existing research or serve as the foundation for new research on the developmental outcomes of pediatric cancer survivors. For future studies, recommendations include increasing the sample size to promote a comprehensive assessment of the cognitive and social-emotional developmental changes that may occur in pedantic cancer survivors. In addition, it could be helpful to have parents of healthy children also complete the questionnaire to provide a group to compare the pediatric cancer survivors with. By surveying healthy children, future researchers will be able to possibly distinguish if developmental changes are normal at certain ages or are directly related to chemotherapy treatment.

**Conclusion**

From the results of this pilot study, it can be inferred that pediatric cancer survivors experience cognitive and social-emotional developmental changes, which may vary based on if the child is currently receiving chemotherapy or has previously received.
chemotherapy, and how long they have been treated with chemotherapy. As the number of pediatric cancer survivors increases, it is essential for healthcare professionals to understand and be aware of possible cognitive and social-emotional developmental changes related to chemotherapy. Through additional research, the knowledge base of health care providers can expand to ultimately improve the effort towards early identification and education about developmental changes related to chemotherapy. Due to the increased number of pediatric cancer survivors, it is essential to work towards better developmental outcomes for these children to improve their overall quality of life.
References


Appendix A

Table 1

<table>
<thead>
<tr>
<th>Years in Remission</th>
<th>Child Age</th>
<th>6-8</th>
<th>13-15</th>
<th>16-18</th>
</tr>
</thead>
<tbody>
<tr>
<td>N/A; my child is still receiving treatment</td>
<td></td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>0-3 years</td>
<td></td>
<td>0</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>More than 10 years</td>
<td></td>
<td>0</td>
<td>0</td>
<td>2</td>
</tr>
</tbody>
</table>

Table 2

<table>
<thead>
<tr>
<th>Years in Remission</th>
<th>Ages</th>
<th>6-8</th>
<th>13-15</th>
<th>16-18</th>
</tr>
</thead>
<tbody>
<tr>
<td>N/A; my child is still receiving treatment</td>
<td>0-3 years</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Doesn’t get along with other kids</td>
<td>Not True</td>
<td>2</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Sometimes True</td>
<td>0</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Very True or Often True</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Too shy or timid</td>
<td>Not True</td>
<td>2</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Sometimes True</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Very True or Often True</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Fails to finish things he/she starts</td>
<td>Did Not Answer</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Not True</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Sometimes True</td>
<td>1</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Very True or Often True</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Confused or seems to be in a fog</td>
<td>Not True</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Sometimes True</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Very True or Often True</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>
Appendix B

Developmental Outcomes of Pediatric Cancer Survivors After Chemotherapy-Survey

What is your gender?
- Male
- Female

What is your age?
- 18-29
- 30-39
- 40-49
- 50-59
- 60-69
- 70+

What is the highest level of school you have completed or the highest degree you have received?
- Less than high school degree
- High school graduate (high school diploma or equivalent including GED)
- Some college but no degree
- Associate degree in college (2-year)
- Bachelor's degree in college (4-year)
- Master's degree
- Doctoral degree
- Professional degree (JD, MD)

What is your child's gender?
- Male
- Female

Choose one or more races that you consider your child to be:
- White
- Black or African American
- American Indian or Alaska Native
- Asian
- Native Hawaiian or Pacific Islander
- Other ____________________
What is the age of your child currently?
○ 0-2
○ 3-5
○ 6-8
○ 9-12
○ 13-15
○ 16-18
○ Other_______________

What was your child's age at time of their diagnosis?
○ 0-2
○ 3-5
○ 6-8
○ 9-12
○ 13-15
○ 16-18
○ Other_______________

What kind(s) of cancer has your child been diagnosed with, either currently or in the past? (Please be as descriptive as possible).
________________________________________________________________________
________________________________________________________________________

How long has your child received treatment for their cancer, including any current or previous treatment?
○ 0-6 months
○ 6 months-1 year
○ 1-3 years
○ 4-5 years
○ 5-10 years
○ 10 or more years

What form(s) of treatment has your child received, either currently or in the past? (Select all that apply).
☐ Chemotherapy
☐ Radiation
☐ Bone Marrow/Stem Cell Treatments
☐ Surgery
☐ Transplant
☐ Other_______________
If applicable, how many years has your child been in remission?
- Not applicable: my child is still receiving treatment
- 0-3 years
- 3-5 years
- 5-8 years
- 8-10 years
- More than 10 years

How many sports, hobbies, activities, jobs, or games does your child participate in?
- None
- 1-3
- 4-6
- 7-9
- More than 10

Please list a few of the sports, hobbies, activities, jobs or games your child participates in the blanks, and answer the following questions. (It is not required to fill in all of the blanks)

<table>
<thead>
<tr>
<th></th>
<th>Compared to others of the same age, about how much time does he/she spend in each?</th>
<th>Compared to others of the same age, how well does he/she do each one?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Less than average</td>
<td>Average</td>
</tr>
<tr>
<td>1.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Please answer the following questions about your child's academic performance.
- Does not attend school because ____________________________________________________________
Check a box for each subject based on how your child is currently performing.

<table>
<thead>
<tr>
<th>Subject</th>
<th>Failing</th>
<th>Below Average</th>
<th>Average</th>
<th>Above Average</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reading, English, or Language Arts</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>History or Social Studies</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Math</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Science</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Foreign Languages</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Electives (gym, computer courses, etc.)</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>

Does your child receive special education or remedial services or attend a special class or special school? Please explain in general terms, using no identifying information.

- No
- Yes- kind of services, class, or school________________________________________
  _______________________________________________________________________
  _______________________________________________________________________

Has your child repeated any grades?

- No
- Yes- grades repeated and reasons_______________________________________________
  ______________________________

Has your child had any academic problems in school?

- No
- Yes-Please describe___________________________________________________________
  ______________________________

Has your child had any behavioral problems in school?

- No
- Yes-Please describe___________________________________________________________
  ______________________________
About how many close friends does your child have? (Do not include brothers & sisters)
- None
- 1
- 2 or 3
- 4 or more

About how many times a week does your child do things with any friends outside of regular school hours? (Do not include brothers & sisters)
- Less than 1
- 1 or 2
- 3 or more

Compared to others of his/her age, how well does your child:

<table>
<thead>
<tr>
<th>Get along with his/her brothers &amp; sisters?</th>
<th>Worse</th>
<th>Average</th>
<th>Better</th>
<th>Not applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Get along with other kids?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Behave with his/her parents?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Play and work alone?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>

Below is a list of items that describe children. For each item, choose the answer that currently best describes your child. Please answer all of the items as well as you can, even if some do not seem to apply to your child.
<table>
<thead>
<tr>
<th>Developmental Outcomes</th>
<th>Not True (as far as you know)</th>
<th>Somewhat or Sometimes True</th>
<th>Very True or Often True</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acts too young for his/her age</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fails to finish things he/she starts</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>There is very little he/she enjoys</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Can't concentrate, can't pay attention for long</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Can't sit still, restless, or hyperactive</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Confused or seems to be in a fog</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Daydreams or gets lost in his/her thoughts</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Feels he/she has to be perfect</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Feels worthless or inferior</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Impulsive acts without thinking</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Overtired without good reason</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Poor school work</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Refuses to talk</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Sleeps less than most kids</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Sleeps more than most kids during day or night</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Inattentive or easily distracted</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Speech problem</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Argues a lot</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Clings to adults or too dependent</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Complains of loneliness</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Disobedient at home</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Disobedient at school</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Doesn't get along with other kids</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Breaks rules at home, school, or elsewhere</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Would rather be alone than with others</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Too shy or timid</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Withdrawn, doesn't get involved with others</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Unhappy, sad, or depressed</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>
For each of the following statements related to your child select: strongly disagree, disagree, neither agree nor disagree, agree, or strongly agree.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither agree nor disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>My child has been limited in schoolwork and activities he/she could do, due to problems experienced during remission.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>My child has been limited in the amount of time spent with friends due to problems experienced during remission.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>My child feels satisfied about their school ability, friendships, and life overall.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Compared to other children of similar age, my child behavior is different because of problems experienced during remission.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

Please elaborate or describe any developmental changes (if any) you have noticed since your child began their cancer treatment. Do not use any identifying information in your response.

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
What concerns you most about your child? Do not use any identifying information in your response.

________________________________________________________________________

________________________________________________________________________

Please describe the best things about your child. Do not use any identifying information in your response.

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________