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Thriving Beyond Surviving: An Examination of the Role Support Groups Play in Enhancing Later Cognitive and Social Development of Pediatric Cancer Patients

Mary MacCarthy
Butler University

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Read, approved, and signed by:

Thesis adviser(s)  4/11/18
Date

Reader(s) Brenda Quay 4/18/18
Date

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Certified by _____
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**Thriving Beyond Surviving: An Examination of the Role Support Groups Play in
Enhancing Later Cognitive and Social Development of Pediatric Cancer Patients**

A Thesis

Presented to the Department of Psychology

College of Liberal Arts and Sciences

and

The Honors Program

of

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In Partial Fulfillment

of the Requirements for Graduation Honors

Mary MacCarthy

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Abstract

Adult survivors of pediatric cancer are at risk of developing “late effects” which are deficiencies in physical, cognitive, and/or social functioning that are usually due to long-term cancer treatment and hospitalization at a young age. These late effects can significantly impact survivors’ well-being and prevent them from leading successful, independent lives. The aim of our research was to investigate whether participation in cancer-related support groups could lessen the impact of late effects. Specifically, we examined whether the degree of engagement with cancer-related support groups was related to the level of cognitive and social functioning in adult pediatric cancer survivors. Through an online questionnaire, we assessed the cognitive ability and social development of 30 adult survivors who had participated in cancer-related support groups. We compared survivors’ scores with published cognitive and social functioning data from the general pediatric cancer survivor population and the general adult population. We also correlated their scores with a measure of their involvement with support groups. Results demonstrated that support group engagement was negatively associated with IQ levels ($r(15) = -.477, p = .053$), marriage status ($r(21) = -.413, p = .05$), and life satisfaction ($t(28) = -2.149, p = .04$), and that cognitive late effects were apparent among adult survivors (Shipley-Hartford: $t(18) = -2.16, p = .044$, Synonym Antonym: $t(19) = -2.854, p = 0.01$). Survivors reported moderately high engagement with their support groups and believed that their groups offered restorative benefits ($M = 23.09, s = 4.36$). Implications of these results include that support groups should continue to be utilized as a means of survivor therapy, and support group administrators should be made aware of

the impact of late effects so that they may implement efforts to help mediate their influence.

Thriving Beyond Surviving: An Examination of the Role Support Groups Play in
Enhancing Later Cognitive and Social Development of Pediatric Cancer Patients

Across the United States, tens of thousands of children are diagnosed with cancer every year (“Key Statistics for Childhood Cancers”, 2016). Fortunately, due to many modern medical advancements, almost eighty percent of these children are able to combat this ordeal and survive into adulthood (“Key Statistics for Childhood Cancers”, 2016). Some pediatric cancer survivors live long, healthy lives after their treatment is completed, but many other patients develop what have come to be known as ‘late effects’. These late effects are deficiencies in physical, cognitive, and/or social functioning that are usually due to long-term cancer treatment and hospitalization (Brinkman et al, 2016). However, these effects often do not manifest or are not recognized until years after treatment has been completed, sometimes not until the survivors are adults (Jacola et al, 2016). Pediatric cancer patients are especially vulnerable to the manifestation of late effects as they have an increased likelihood of interruptions in physical, cognitive, and social development due to receiving treatment at a young, malleable age (Brinkman et al, 2016).

Most of the research that has explored the presence of late effects in pediatric cancer survivors has suggested various ways to decrease the influence of these effects such as implementing different cancer treatment methods or using later remedial tasks to help increase the adult survivor’s functioning (Brinkman et al, 2016). However, one late effect treatment possibility that has not been widely explored is the implementation of adult pediatric cancer survivor support groups (Brinkman et al, 2014; Kunin-Batson, Kadan-Lottick, & Neglia, 2014; Ruiter et al, 2015; Jacola et al, 2016). By participating in

support groups that pertain to their situation and afflictions, pediatric cancer survivors who developed late effects could potentially regain some of their social and cognitive functioning and decrease the impact that the late effects had on their lives or at least develop strategies to cope with them more effectively. Being surrounded by and communicating with others who had experienced similar hardships and limitations could allow survivors to prevent further social and cognitive skill decline.

Significance

Due to increasingly better medical technology, more children are surviving their cases of pediatric cancer and living longer lives, but they are therefore also at a greater risk for developing late effects (Brinkman et al, 2016). As the risk of developing late effects increases, more methods need to be identified that can either help prevent or remedy the onset of these effects and the impact they have on survivors' lives. One such method of decreasing the influence of these late effects could be through the utilization of support groups. If survivors who utilized cancer-related support groups showed fewer signs of cognitive or social deficits, it could be beneficial to invest more efforts into expanding the size and availability of the groups in order to help more people. Psychologists, physicians, and other healthcare providers who work with these pediatric cancer survivors could provide more information and place more emphasis on urging their patients to seek support groups in order to lessen any unintended effects from their treatment and hospitalization.

Literature Review

Cognitive Functioning Late Effects

Extensive research has been conducted that indicates the presence of cognitive deficits in adult pediatric cancer survivors (Edelmann et al, 2013; Kunin-Batson et al, 2014; Prasad et al, 2015; Edelmann et al, 2016). Many studies have shown that adult pediatric cancer survivors have significantly decreased functioning in various cognitive skills such as memory, attention, intelligence, and executive functioning when compared with the general population (Edelmann et al, 2013; Brinkman et al, 2016; Edelmann et al, 2016; Jacola et al, 2016). To control for variations in natural baseline cognitive ability, other research efforts have compared mental functions in adult pediatric cancer survivors to capabilities of their healthy siblings and have found that survivors still report more cognitive deficits (Jacola et al, 2016). This indicates that the loss of normal mental functioning experienced by survivors is due to their adverse medical experiences and not to genetic predispositions. Previous research has also found that cognitive deficits appear in survivors who suffered from a wide range of cancer types and underwent various forms of treatment, even those that did not directly affect the central nervous system (Brinkman et al, 2016; Edelmann et al, 2016). The interrupted development caused by treatment and hospitalization in pediatric patients appears to broadly increase survivors' risk of developing late effects, regardless of their specific therapy exposure. This unfortunately also indicates that the disruption caused by late effects is fairly widespread. These cognitive deficits have been associated with deficiencies in various other aspects of survivors' lives as well which have broader implications for their ability to lead independent lives.

Social Functioning Late Effects

Many recent studies have shown that the late effect cognitive deficits that many adult pediatric cancer survivors suffer from are associated with deficits in social functioning (Moyer et al, 2012; Crom et al, 2014; Kunin-Batson, 2014; Ruiter et al, 2015). Survivors with impaired cognition have been reported as less likely to be employed, less likely to live independently, and more likely to be single (Crom et al, 2014). Cognitive deficits are also associated with the behavior of survivors, and research has shown that impaired mental processing has been linked with a higher likelihood for headstrong behavior and social withdrawal (Jacola et al, 2016). It appears as if survivors' cognitive limitations may be linked with functioning in socially-unacceptable ways which affects their ability to live as independent adults.

These social deficiencies have also been shown to occur in adult pediatric cancer survivors who did not experience significant cognitive deficits. Former patients who showed no signs of mental deficiencies still shared concerns about their abilities to lead normal, independent lives and achieve expected adult milestones such as creating a stable, supportive marriage (Thompson, Long, & Marsland, 2013). This indicates that social deficits experienced by adult pediatric cancer survivors may be linked not only to treatments, but also to their hospitalization and disruption of typical social development. Previous studies have also shown that social deficits are apparent in survivors who endured a wide variety of cancer and treatment types which indicates that the social impact that survivors experience is widespread (Crom et al, 2014; Berbis et al, 2016). Interventions should be applied to help remedy the late effects that are causing these decreases in functioning and life satisfaction, and this could be completed through the utilization of support groups.

Support Group Benefits

Considerable research has been conducted that has illustrated the positive and healing effects of support groups. Participants from a wide variety of support group-types concerning topics such as, but not limited to, cancer, grief, and pregnancy have all reported that their engagement in their groups has benefited their lives and wellbeing (Elder & Burke, 2015; Gabbe et al, 2017). Recent studies have shown that support groups aid their participants through a variety of measures such as offering psychological support, helping share information and education, restoring dignity and confidence, changing behaviors, helping form friendships, and providing tools to learn new skills (Olliffe et al, 2015; Rasool & Ross, 2017). Many support groups pertaining to specific situations or diseases have notably assisted their participants by helping them connect with others who share their situation and helping “normalize” their unusual experiences by providing tools for discussion and reflection (Elder & Burke, 2015; Rasool & Ross, 2017). Support groups provide evident positive benefits to their members and could therefore possibly aid adult pediatric cancer survivors by decreasing the impact of late effects.

Current Study

Although many pediatric cancer patients do survive into adulthood, many survivors later face afflictions due to interrupted development caused by their treatments. Substantial research has illustrated the presence of these deficiencies and the necessity of investigating methods to lessen their effects. Previous studies have also indicated that support groups play important roles in aiding people in recovering from traumas and ailments. Through utilization of their resources and encouraging communities, support

groups could assist pediatric cancer survivors with the management of their late effects. Using an online questionnaire format, we explored whether adult survivors of pediatric cancer who actively participated in cancer-related support groups showed fewer cognitive deficits and better social adjustment than cancer survivors from the general population. Specifically, we proposed that the degree of engagement with cancer-related support groups was positively related to the level of cognitive and social functioning in adult pediatric cancer survivors.

Methods

Participants

30 participants were assessed as part of the study (not all participants completed all components of the questionnaire, so participants' data was only included in analysis for the items they completed). All participants confirmed they were at least 18 years old and had been previously diagnosed with pediatric cancer. They gave consent and willingly chose to take part in the study, and they were not compensated for their time. Participant demographics are summarized in Table 1. 25 participants reported they were female, and five participants reported they were male. The ages of participants ranged from 21 to 47 years old ($M = 31.03$). Participants were relatively well educated as 53.3 percent had earned a bachelor's degree or higher and only 3.3 percent had not completed high school. Only ten percent disclosed they were unable to work, and all other participants were either employed or willingly not working (a homemaker, a student, etc.). The majority of participants were single (never married) and made less than \$25,000 a year. Pediatric cancer diagnoses varied greatly, but the most common forms were acute lymphoblastic leukemia, neuroblastoma, and nephroblastoma.

Table 1

Summary of Adult Pediatric Cancer Survivor Characteristics

	Frequency	Percentage
Gender		
Male	5	16.7
Female	25	83.3
Age		
21-29 years old	15	50.0
30-39 years old	11	36.7
40-47 years old	4	13.3
Education Level		
Some high school	1	3.3
High school graduate	3	10.0
Some college	5	16.7
Vocational training	1	3.3
Associate degree	4	13.3
Bachelor's degree	7	23.3
Some graduate credit	2	6.7
Graduate degree	7	23.3
Employment Status		
Employed for wages	22	73.3
Self-employed	2	6.7
Homemaker	2	6.7
Student	1	3.3
Unable to work	3	10.0
Total Income		
Less than \$25,000	15	50.0
\$25,000 to \$49,999	9	30.0
\$50,000 to \$74,999	3	10.0
\$75,000 to \$99,999	1	3.3
\$100,000 to \$149,999	1	3.3
\$150,000 or more	1	3.3
Marital Status		
Single	17	56.7
Married	13	43.3

Materials

The study was conducted through an online questionnaire that was created and compiled through a web-based Qualtrics interface. As part of the study, participants were asked to complete a variety of measures. The measures were broken down into four major areas: 1) demographics, 2) cognitive ability 3) general social development and life satisfaction, and 4) cancer-related support group participation and engagement. The items from the demographics and support group sections are presented in Appendices A and B respectively.

Demographic questions consisted of the participant's age, sex, pediatric cancer diagnosis, education level, employment status, marital status, and annual income (Appendix A). The cognitive functioning measures consisted of the Shipley-Hartford Test (Shipley & Burlingame, 1941) to assess general IQ and the Synonym Antonym Test (Salthouse, Atkinson, & Berish, 2003) to assess executive functioning. The Shipley-Hartford test measures general intelligence by assessing how accurately participants can complete a series of 60 pattern and word recognition exercises (Shipley & Burlingame, 1941), and the Synonym Antonym Test determines functioning by measuring how effectively participants can switch between 20 synonym and antonym identifying tasks (Salthouse et al, 2003).

To measure social development and functioning, the Satisfaction with Life Scale (Diener et al., 1985) was utilized along with the education, employment, and marital status demographic questions. The Satisfaction with Life Scale ($\alpha = 0.91$) is a five-item questionnaire that consists of statements to which participants rate their level of agreement using a seven-point Likert-scale (strongly agree to strongly disagree) (Diener

et al., 1985). Examples of these statements include “In most ways my life is close to my ideal” and “I am satisfied with my life”. Support group participation and engagement were evaluated through an eight-item questionnaire ($\alpha = 0.81$). Four of the questions also utilized a Likert-scale and consisted of statements to which participants would respond with their level of agreement (strongly agree to strongly disagree). Examples of these statements include: “I felt supported by this support group” and “I met other people who had similar experiences to me through this support group” (Appendix B).

Procedure

Invitations to participate in the study were sent out to various cancer support groups across the nation asking them to share the study with their members. These requests contained a link to the Qualtrics questionnaire, information about the study, and our contact information in case the support groups and/or support group members had further questions about our research. Invitations were sent via email and Facebook message and were followed by phone calls to the support group organizations when their contact information was available. Requests were then re-sent monthly to remind and further encourage support groups and their members to participate in the study. Some of the support groups we contacted met online while others met in-person, and some pertained specifically to pediatric cancer survivors while others applied to more general cancer survivors. To ensure that only eligible survivors participated in the study, the questionnaire and research information contained specific instructions that participation was sought only from individuals who were diagnosed with some form of cancer prior to the age of eighteen and who were currently at least eighteen years old.

Statistical Analysis

Participant demographic data was evaluated through descriptive statistics. The Shipley-Hartford Test and Synonym Antonym Test scores were calculated by determining how many of the exercises each participant scored correctly (Shipley & Burlingame, 1941; Salthouse, Atkinson, & Berish, 2003). Higher scores indicated greater cognitive functioning. The Satisfaction with Life Scale and support group engagement scores were determined by converting the Likert-scale responses to numerical values (strongly disagree = 1 and strongly agree = 7) and then adding the values from each statement (Diener et al., 1985). Higher scores illustrated greater life satisfaction and greater support group engagement.

The levels of cognitive and social deficits reported by survivors who participated in support groups were compared to healthy individuals (i.e., the tests' published national norms) (Shipley & Burlingame, 1941; Pavot, Diener, Colvin, & Sandvik, 1991; Salthouse et al, 2003) through t-test analysis. The social functioning measures were also compared to available data from previous studies examining pediatric cancer survivors (Calaminus et al, 2014; Crom et al, 2014) through chi-square goodness-of-fit tests. Pearson correlation procedures were utilized to determine any relationships between levels of cognitive and social deficiencies and support group engagement. A *p*-value of less than .05 was considered statistically significant.

Results

Cognitive Functioning

Cognitive functioning test scores are summarized in Table 2. Comparisons of the participants' scores to previous research is demonstrated in Figure 1. Participants' scores on the Shipley-Hartford Test ($M = 57.74, s = 12.63$) were significantly lower than

published data from the general population ($t(18) = -2.16, p = .044$), indicating a lower IQ among the surveyed survivors (Shipley & Burlingame, 1941). Scores on the Synonym Antonym Test ($M = 4.10, s = 1.41$) were also significantly lower than previously reported scores from healthy adults ($t(19) = -2.854, p = 0.01$), indicating that participants demonstrated lower levels of executive functioning than the normal population (Salthouse et al, 2003).

Table 2

Summary of Means and Standard Deviations for Scores on Shipley-Hartford Test, Synonym Antonym Test, Satisfaction with Life Scale, and Support Group Engagement

	Mean	Standard Deviation
Shipley-Hartford Test	57.74	12.63
Synonym Antonym Test	4.10	1.41
Satisfaction with Life Scale	23.90	7.28
Support Group Engagement	23.09	4.36

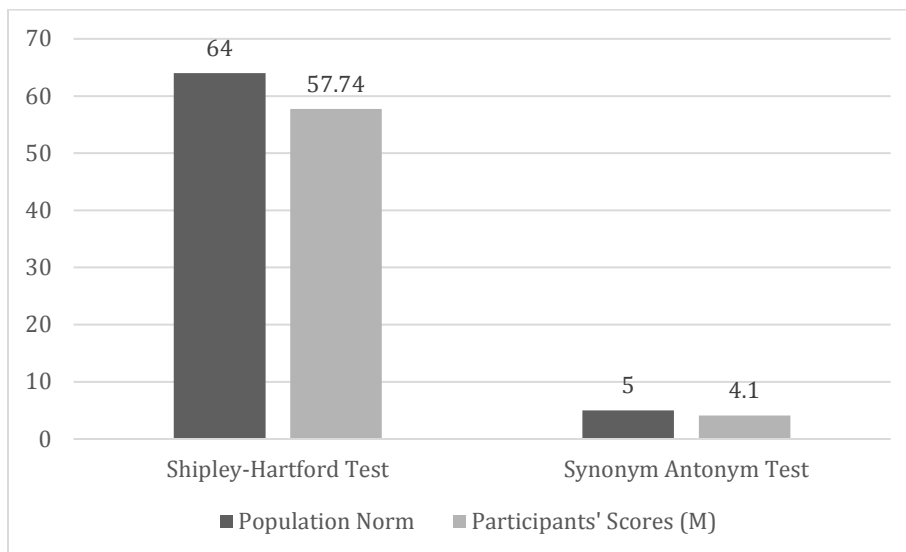


Figure 1: Mean participant and population scores on the Shipley-Hartford and Synonym Antonym tests.

Social Functioning

Social functioning scores are summarized in Table 2. Comparisons of the participants' scores to previous research is demonstrated in Figure 2. Participants reported moderately high life satisfaction on The Satisfaction with Life Scale, specifically that they were "slightly satisfied" ($M = 23.90, s = 7.28$). Their ratings were not significantly different from general population norms ($t(28) = -.225, p = .824$) demonstrating that the survivors were similarly satisfied with their lives compared to normal adults (Pavot et al, 1991). However, when compared with previous studies that have examined pediatric cancer patients (Crom et al, 2014), participants' life satisfaction scores were significantly lower ($t(28) = -2.149, p = .04$). This indicated that survivors who participated in support groups were less satisfied with their lives than their cancer survivor peers. Conversely, when compared with past studies (Calaminus et al, 2014), education levels ($\chi^2(2, n = 30) = 4.70, p = .096$), marital status ($\chi^2(2, n = 30) = .009, p = .925$), and employment status ($\chi^2(1, n = 30) = .958, p = .328$) did not significantly differ between adult pediatric cancer survivors who were and were not members of support groups. This suggested that some aspects of social functioning were consistent among all adult survivors.

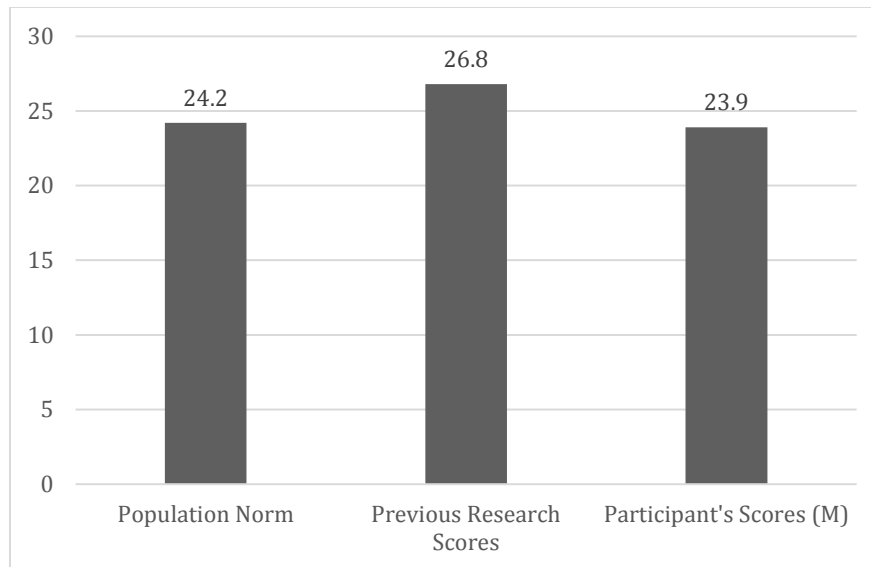


Figure 2: Mean participant, population, and general pediatric cancer survivor (Crom et al, 2014) scores on the Satisfaction with Life Scale.

Support Group Engagement

Support group engagement scores are summarized in Table 2. All survivors who were included in the study were members of cancer-related support groups. Participants reported that they felt moderately supported and engaged by their respective groups ($M = 23.09, s = 4.36$).

Correlational Results

Correlation values are summarized in Table 3. Correlational analysis revealed a moderately strong negative relationship between the level of engagement with support groups and the level of accuracy on the Shipley-Hartford Test ($r(15) = -.477, p = .053$). This suggested that participants who felt more included and supported by their support groups demonstrated lower IQs. A moderately strong negative relationship was also found between the level of support group engagement and marital status ($r(21) = -.413, p = .05$). This indicated that participants who felt more bolstered by their support groups

were less likely to be married. The level of support group engagement did not result in strong correlations for the Synonym Antonym Test ($r(16) = .056, p = .826$), the Satisfaction with Life Scale ($r(21) = -.023, p = .916$), or the demographic level of education ($r(21) = -.064, p = .773$). Because there were no participants who were unwillingly unemployed, no correlational analysis with support group engagement and employment status was conducted.

One other significant association was discovered between life satisfaction and education level as they revealed a moderately strong, positive relationship ($r(27) = .369, p = .049$). This indicated that participants who reported they were more educated also reported being more satisfied with their lives. Similar patterns of a positive association, albeit not significant, were also seen between life satisfaction and the Shipley-Hartford ($r(17) = .326, p = .173$) and Synonym Antonym Test scores ($r(18) = .246, p = .296$). This suggested that participants who scored higher on the measures of cognitive functioning were not reliably more content with the state of their lives.

Table 3:

Summary of Correlations for Scores on Shipley-Hartford Test, Synonym Antonym Test, Satisfaction with Life Scale, Support Group Engagement, Education Level, and Marital Status

	Shipley-Hartford Test	Synonym Antonym Test	Satisfaction with Life Scale	Support Group Engagement	Education Level	Marital Status
Shipley-Hartford Test	$r = 1$ $n = 19$	$r = .144$ $p = .556$ $n = 19$	$r = .326$ $p = .173$ $n = 19$	$r = -.477$ $p = .053$ $n = 17$	$r = .474$ $p = .040$ $n = 19$	$r = .235$ $p = .333$ $n = 19$
Synonym	$r = .144$	$r = 1$	$r = .246$	$r = .056$	$r = -.079$	$r = -.356$

Antonym Test	$p = .556$ $n = 19$	$n = 20$	$p = .296$ $n = 20$	$p = .826$ $n = 18$	$p = .741$ $n = 20$	$p = .123$ $n = 20$
Satisfaction with Life Scale	$r = .326$ $p = .173$ $n = 19$	$r = .246$ $p = .296$ $n = 20$	$r = 1$ $n = 29$	$r = -.023$ $p = .916$ $n = 23$	$r = .369$ $p = .049$ $n = 29$	$r = .267$ $p = .162$ $n = 29$
Support Group Engagement	$r = -.477$ $p = .053$ $n = 17$	$r = .056$ $p = .826$ $n = 18$	$r = -.023$ $p = .916$ $n = 23$	$r = 1$ $n = 23$	$r = -.064$ $p = .773$ $n = 23$	$r = -.413$ $p = .050$ $n = 23$
Education Level	$r = .474$ $p = .040$ $n = 19$	$r = -.079$ $p = .741$ $n = 20$	$r = .369$ $p = .049$ $n = 29$	$r = -.064$ $p = .773$ $n = 23$	$r = 1$ $n = 30$	$r = -.015$ $p = .939$ $n = 30$
Marital Status	$r = .235$ $p = .333$ $n = 19$	$r = -.356$ $p = .123$ $n = 20$	$r = .267$ $p = .162$ $n = 29$	$r = -.413$ $p = .050$ $n = 23$	$r = -.015$ $p = .939$ $n = 30$	$r = 1$ $n = 30$

Discussion

Through our pursuit to determine the nature of the association between degree of involvement in cancer-related support groups by adult pediatric cancer survivors and their levels of cognitive and social functioning, we have identified a few primary findings. Support group engagement is negatively associated with levels of IQ, marital status, and life satisfaction, and late effects are present among adult survivors.

Contrary to our hypothesis that the degree of engagement in support groups would be positively linked to functioning, support group participation appeared to be significantly, negatively associated with IQ abilities (scores on the Shipley-Hartford measure). We can conclude that those who felt more supported and included through support group engagement exhibited certain weaker cognitive abilities. While we cannot determine the temporal relation of support group participation and cognitive decline due to the cross-sectional design of our study, one possible explanation for this pattern is that

those who had greater cognitive deficiencies sought out support groups to find assistance and encouragement with handling their cognitive limitations. Previous research has demonstrated that support groups can benefit participants by augmenting their education and ability to learn new skills (Oliffe et al, 2015; Rasool & Ross, 2017). Through their support groups, survivors could have learned more about cognitive late effects and could have been trained in different coping mechanisms to prevent cognitive deficits from largely influencing their lives. This would allow survivors to still receive mental benefits from support group engagement even if their cognitive abilities did not necessarily increase. Fortunately, this negative relationship was not present between support group engagement and executive functioning (scores on the Synonym Antonym measure). No significant association existed between the two factors. Although contrary to our hypothesis, this pattern demonstrated that survivors who seek out support groups may not be notably limited in all aspects of cognitive abilities. If survivors do not join support groups to enhance their executive functioning, then treatment guidelines for mental late effects could be streamlined to focus on mediating IQ.

Similar to the Shipley-Hartford scores, life satisfaction (scores on the Satisfaction with Life scale) was also not positively associated with support group engagement. Specifically, when compared to the general population of pediatric cancer survivors, those who participated in support groups appeared to have significantly worse life satisfaction. This finding directly opposed our hypothesis that support group engagement would be positively linked with greater social functioning. One possible explanation for this deviation is that those who possessed more negative emotions towards their lives may have been more inclined to participate in a support group. Survivors who felt less

satisfied with the course of their lives may have sought support group engagement to address their perceived lack of fulfillment and to discover ways to gain a more positive outlook. Prior studies have shown that people often reach out to support groups specifically to find ways to improve their outlook and attitudes and to restore their confidence and sense of purpose (Elder & Burke, 2015; Wang et al, 2015). Participation in support groups could allow survivors to become more satisfied with their lives.

Support group engagement was also associated with lower rates of marriage among adult survivors. This finding also contradicted our hypothesis, but similar to life satisfaction, survivors could be utilizing support groups to improve their social skills to assist them in maintaining meaningful relationships. Past research has demonstrated that support groups assist members in forming friendships and connecting with others who have endured similar experiences (Elder & Burke, 2015; Rasool & Ross, 2017). Support group participation could allow survivors to work through their current limitations so they could eventually create lasting connections. Although these participants reported lower social functioning, they could be utilizing support groups to move past their disadvantages and in turn mediate possible late effects.

Regardless of the link between support group engagement and cognitive and social deficiencies, our findings did further support the notion that pediatric cancer survivors develop late effects during their adult years. Participants' Shipley-Hartford and Synonym Antonym scores were considerably lower than population norms indicating that their cognitive functioning was lower than what would be expected from healthy adults. Their pediatric cancer diagnosis appeared to be linked to their deficits in cognitive ability. This finding is comparable to previous research on late effects that has discovered

cognitive deficiencies in many adult survivors, especially in IQ and executive functioning (Edelmann et al, 2013; Brinkman et al, 2016, Edelmann et al, 2016; Jacola et al, 2016).

Late effects related to social functioning also appeared to be moderately present among participants. Although the differences were not significant, participants reported lower life satisfaction scores than what were typically conveyed by normal adults, and the majority were unmarried. Aspects of participants' social functioning, similar to their cognitive functioning, appeared to be associated with their status as a pediatric cancer survivor. Previous studies have demonstrated that adult survivors are less likely than adults from the general population to be married (Calaminus et al, 2014) and to be satisfied with the course of their lives (Crom et al, 2014). Conversely, participants did not appear to deviate in terms of their education or employment as the majority of survivors had received a college education and very few survivors were unable to work. While prior research has indicated differences in education and employment between pediatric cancer survivors and the general population (Calaminus et al, 2014; Crom et al., 2014), other studies have demonstrated that there are not always large deficiencies (Nagarajan et al, 2004, Berbis et al, 2016). These findings illustrate that not all pediatric cancer survivors face social late effects in their academic and professional careers. Fortunately, our sample of survivors appeared to have maintained these aspects of their social functioning.

In addition to our hypothesized associations, a positive relationship was discovered between the life satisfaction and education level scales. This link indicated that as participants' education level increased, life satisfaction increased. This pattern was further supported by moderately strong (though not significant), positive relationships

between life satisfaction and Shipley-Hartford and Synonym Antonym scores. Previous research has demonstrated supportive findings that as intelligence and education increase, life satisfaction and general happiness typically also increase (Voracek, 2009; Ali et al, 2012). Survivors who are more educated have likely received more opportunities and maintained greater cognitive ability and are therefore more satisfied with their lives.

Limitations

There were some limitations present within our study that could have influenced our results. One such limitation was our small sample size. Because we were surveying a very specific population, it was difficult to locate large groups of survivors who were willing to participate. Our smaller number of participants may have prevented us from discerning stronger relationships between support group engagement and cognitive and social functioning. Our small sample size also may have prevented us from adequately including the varying characteristics of individuals within the survivor population (such as race, socioeconomic status, or geographic location) which could limit the generalizability of our findings.

Our results also could have been affected by the perceived difficulty of the instruments we utilized for our study. When the survey requests were sent out to support groups, a handful of administrators expressed concerns that their support group members would feel intimidated by the pattern and word recognition exercises in the Shipley-Hartford and Synonym Antonym tests. While these measures are designed for use by the general public, they do contain certain questions that are purposefully more difficult in order to distinguish different levels of cognitive ability (Shipley & Burlingame, 1941; Salthouse, Atkinson, & Berish, 2003). However, if the exercises were viewed by

participants as intimidating, those with less cognitive functioning may have felt less inclined to participate and/or complete the cognitive sections. Our findings could therefore lack their scores and portray the average cognitive functioning of adult survivors in support groups as greater than what is true. If this possible limitation did influence our results, then the cognitive effect of late effects could be even greater than what is reported here.

Future Directions

Expansion of this research could further explore the benefits that support groups provide to pediatric cancer survivors suffering from late effects. One possibility for future investigation could be to implement a longitudinal study design instead of a cross-sectional method. Due to time and resource restraints, our research employed a cross-sectional design that only evaluated the pediatric cancer survivors at one point in time. This restricted our assessment of the participants to their current states and prevented us from examining the progression of any present late effects over time. By utilizing a longitudinal method, we could better examine how participants' cognitive and social functioning fluctuated in relation to their engagement with a support group. If any increase in cognitive or social functioning was demonstrated, we could more thoroughly investigate the relationship between the improvements and support group participation.

Another opportunity for expansion could be to investigate how the setting of support groups, particularly in-person and online, influences the presence of cognitive and social late effects. Our research did not differentiate between support group types and instead examined the link between functioning and any form of support group engagement. However, previous research has demonstrated that in-person support groups

can be more effective than online groups when treating certain ailments such as drug addictions (Grant & Dill-Shackleford, 2017). Prior studies have also shown that relationships formed in-person can be more supportive and longer lasting than those created online (Blunt-Vinti, Wheldon, Mcfarlane, Brogan, & Walsh-Buhi, 2016). It is therefore possible that in-person cancer-related support groups could more effectively address late effects and help build better social connections for adult survivors than online support groups. If support group settings do play a role in their effectiveness, then a stronger relationship could potentially be discovered between in-person support group engagement and cognitive and social functioning.

Implications

Support group engagement, while not strongly associated with all aspects of late effects, did appear to offer some therapeutic benefits. Survivors' cognitive functioning was associated with their degree of participation which demonstrated that survivors may utilize support groups to help manage mental late effects. Participants also reported feeling generally supported and benefited by the groups they joined which illustrated that support groups enhanced survivors' well-being outside of mediating late effects. When compared to other pediatric cancer survivors and the general healthy population, cancer survivors engaged in support groups not only provided evidence of late effects but also differed on many measures of demographics and cognitive and social functioning, indicating that they were a defined group with specific characteristics and needs.

Regardless of the exact benefits, support groups did appear to assist survivors in working towards happier and healthier lives and should therefore continue to be utilized as a therapeutic means. Administrators and counselors leading support groups should be

made aware of the possible presence of late effects among their survivors and should consider catering activities and discussions to help mediate their influences. By implementing practices to combat the detrimental influence of late effects, the cancer community can help those diagnosed with pediatric cancer do more than just survive their ailments; they can help them reclaim their lives and truly thrive.

References

- Ali, A., Ambler, G., Strydom, A., Rai, D., Cooper, C., Mcmanus, S., . . . Hassiotis, A. (2012). The relationship between happiness and intelligent quotient: The contribution of socio-economic and clinical factors. *Psychological Medicine*, 43(06), 1303-1312. doi:10.1017/s0033291712002139
- Berbis, J., Reggio, C., Michel, G., Chastagner, P., Bertrand, Y., Kanold, J., . . . Auquier, P. (2016). Employment in French young adult survivors of childhood leukemia: an LEA study (for Leucemies de l'Enfant et de l'Adolescent—childhood and adolescent leukemia). *Journal of Cancer Survivorship*, 10(6), 1058-1066. doi:10.1007/s11764-016-0549-0
- Blunt-Vinti, H. D., Wheldon, C., Mcfarlane, M., Brogan, N., & Walsh-Buhi, E. R. (2016). Assessing Relationship and Sexual Satisfaction in Adolescent Relationships Formed Online and Offline. *Journal of Adolescent Health*, 58(1), 11-16. doi:10.1016/j.jadohealth.2015.09.027
- Brinkman, T. M., Krasin, M. J., Liu, W., Armstrong, G. T., Ojha, R. P., Sadighi, Z. S., . . . Krull, K. R. (2016). Long-Term Neurocognitive Functioning and Social Attainment in Adult Survivors of Pediatric CNS Tumors: Results from the St Jude Lifetime Cohort Study. *Journal of Clinical Oncology*, 34(12), 1358-1367. doi:10.1200/jco.2015.62.2589
- Brinkman, T. M., Merchant, T. E., Li, Z., Brennan, R., Wilson, M., Hoehn, M. E., . . . Krull, K. R. (2014). Cognitive function and social attainment in adult survivors of retinoblastoma: A report from the St. Jude Lifetime Cohort Study. *Cancer*, 121(1), 123-131. doi:10.1002/cncr.28924

- Calaminus, G., Dörffel, W., Baust, K., Teske, C., Riepenhausen, M., Brämswig, J., . . . Schellong, G. (2014). Quality of life in long-term survivors following treatment for Hodgkin's disease during childhood and adolescence in the German multicentre studies between 1978 and 2002. *Supportive Care in Cancer*, 22(6), 1519-1529. doi:10.1007/s00520-013-2114-y
- Crom, D. B., Li, Z., Brinkman, T. M., Hudson, M. M., Armstrong, G. T., Neglia, J., & Ness, K. K. (2014). Life Satisfaction in Adult Survivors of Childhood Brain Tumors. *Journal of Pediatric Oncology Nursing*, 31(6), 317-326. doi:10.1177/1043454214534532
- Diener, E., Emmons, R. A., Larsen, R. J., & Griffin, S. (1985). The Satisfaction with Life Scale. *Journal of Personality Assessment*, 49, 71-75. doi:10.1207/s15327752jpa4901_13
- Edelmann, M. N., Daryani, V. M., Bishop, M. W., Liu, W., Brinkman, T. M., Stewart, C. F., . . . Krull, K. R. (2016). Neurocognitive and Patient-Reported Outcomes in Adult Survivors of Childhood Osteosarcoma. *JAMA Oncology*, 2(2), 201. doi:10.1001/jamaoncol.2015.4398
- Edelmann, M. N., Ogg, R. J., Scoggins, M. A., Brinkman, T. M., Sabin, N. D., Pui, C., . . . Krull, K. R. (2013). Dexamethasone exposure and memory function in adult survivors of childhood acute lymphoblastic leukemia: A report from the SJLIFE cohort. *Pediatric Blood & Cancer*, 60(11), 1778-1784. doi:10.1002/pbc.24644
- Elder, J., & Burke, L. A. (2015). Parental Grief Expression in Online Cancer Support Groups. *Illness, Crisis & Loss*, 23(2), 175-190. doi:10.1177/1054137315576617

Gabbe, P. T., Reno, R., Clutter, C., Schottke, T. F., Price, T., Calhoun, K., . . . Lynch, C.

D. (2017). Improving Maternal and Infant Child Health Outcomes with Community-Based Pregnancy Support Groups: Outcomes from Moms2B Ohio. *Maternal and Child Health Journal*. doi:10.1007/s10995-016-2211-x

Grant, D. S., & Dill-Shackleford, K. E. (2017). Using social media for sobriety recovery:

Beliefs, behaviors, and surprises from users of face-to-face and social media sobriety support. *Psychology of Popular Media Culture*, 6(1), 2-20. doi:10.1037/ppm0000126

Jacola, L. M., Edelstein, K., Liu, W., Pui, C., Hayashi, R., Kadan-Lottick, N. S., . . .

Krull, K. R. (2016). Cognitive, behaviour, and academic functioning in adolescent and young adult survivors of childhood acute lymphoblastic leukaemia: a report from the Childhood Cancer Survivor Study. *The Lancet Psychiatry*, 3(10), 965-972. doi:10.1016/s2215-0366(16)30283-8

Key Statistics for Childhood Cancers. (2016, August 22). Retrieved January 31, 2017,

from <https://www.cancer.org/cancer/cancer-in-children/key-statistics.html>

Kunin-Batson, A., Kadan-Lottick, N., & Neglia, J. P. (2014). The contribution of

neurocognitive functioning to quality of life after childhood acute lymphoblastic leukemia. *Psycho-Oncology*, 23(6), 692-699. doi:10.1002/pon.3470

Moyer, K. H., Willard, V. W., Gross, A. M., Netson, K. L., Ashford, J. M., Kahalley, L.

S., . . . Conklin, H. M. (2012). The impact of attention on social functioning in survivors of pediatric acute lymphoblastic leukemia and brain tumors. *Pediatric Blood & Cancer*, 59(7), 1290-1295. doi:10.1002/pbc.24256

Nagarajan, R., Clohisy, D. R., Neglia, J. P., Yasui, Y., Mitby, P. A., Sklar, C., . . .

Robison, L. L. (2004). Function and quality-of-life of survivors of pelvic and lower extremity osteosarcoma and Ewings sarcoma: The Childhood Cancer Survivor Study. *British Journal of Cancer*, *91*(11), 1858-1865.

doi:10.1038/sj.bjc.6602220

Oliffe, J. L., Chambers, S., Garrett, B., Bottorff, J. L., McKenzie, M., Han, C. S., &

Ogrodniczuk, J. S. (2015). Prostate Cancer Support Groups. *American Journal of Men's Health*, *9*(2), 163-172. doi:10.1177/1557988314543510

Pavot, W., Diener, E., Colvin, C. R., & Sandvik, E. (1991). Further validation of the

Satisfaction with Life Scale: Evidence for the cross-method convergence of well-being measures. *Journal of Personality Assessment*, *57*, 149-161

Prasad, P. K., Hardy, K. K., Zhang, N., Edelstein, K., Srivastava, D., Zeltzer, L., . . .

Krull, K. (2015). Psychosocial and Neurocognitive Outcomes in Adult Survivors of Adolescent and Early Young Adult Cancer: A Report from the Childhood Cancer Survivor Study. *Journal of Clinical Oncology*, *33*(23), 2545-2552.

doi:10.1200/jco.2014.57.7528

Rasool, S., & Ross, E. (2017). The Power and Promise of Group Work. *Research on*

Social Work Practice, *27*(2), 206-214. doi:10.1177/1049731516653185

Ruiter, M. A., Meeteren, A. Y., Vuurden, D. G., Maurice-Stam, H., Gidding, C., Beek, L.

R., . . . Grootenhuis, M. A. (2015). Psychosocial profile of pediatric brain tumor survivors with neurocognitive complaints. *Quality of Life Research*, *25*(2), 435-

446. doi:10.1007/s11136-015-1091-7

- Salthouse, T. A., Atkinson, T. M., & Berish, D. E. (2003). Executive Functioning as a Potential Mediator of Age-Related Cognitive Decline in Normal Adults. *Journal of Experimental Psychology: General*, 132(4), 566-594. doi:10.1037/0096-3445.132.4.566
- Shipley, W. C., & Burlingame, C. C. (1941). A Convenient Self-Administering Scale for Measuring Intellectual Impairment in Psychotics. *American Journal of Psychiatry*, 97(6), 1313-1325. doi:10.1176/ajp.97.6.1313
- Thompson, A. L., Long, K. A., & Marsland, A. L. (2013). Impact of Childhood Cancer on Emerging Adult Survivors' Romantic Relationships: A Qualitative Account. *The Journal of Sexual Medicine*, 10, 65-73. doi:10.1111/j.1743-6109.2012.02950.x
- Voracek, M. (2009). National Intelligence, Suicide Rate, and Subjective Well-Being. *Perceptual and Motor Skills*, 109(3), 718-720. doi:10.2466/pms.109.3.718-720
- Wang, J., Zhang, T., Shen, Q., Yang, Z., Liu, C., Chen, S., . . . Yu, J. (2015). The experience of cancer survivors in community-based psycho-social support activities in Shanghai, China: a qualitative study. *Quality of Life Research*, 24(12), 2815-2822. doi:10.1007/s11136-015-1021-8

Appendix A

Demographics Questionnaire

1. Age:
2. When you were a child (under 18 years old), did you at some point develop cancer?
 - a. Yes
 - b. No
3. What was your official pediatric cancer diagnosis?:
4. What is your gender?
 - a. Male
 - b. Female
 - c. Other/Prefer not to answer
5. What is your education level?
 - a. Some high school, no diploma
 - b. High school graduate or the equivalent (example: GED)
 - c. Some college but no degree
 - d. Trade/technical/vocational training
 - e. Associate degree
 - f. Bachelor's degree
 - g. Some graduate credit, no graduate degree
 - h. Graduate degree
6. What is your current employment status?
 - a. Employed for wages

- b. Self-employed
 - c. Out of work and looking for work
 - d. Out of work but not currently looking for work
 - e. A homemaker
 - f. A student
 - g. Retired
 - h. Unable to work
7. What was your total income during the past 12 months (before taxes)?
- a. Less than \$25,000
 - b. \$25,000 to \$49,999
 - c. \$50,000 to \$74,999
 - d. \$75,000 to \$99,999
 - e. \$100,000 to \$149,999
 - f. \$150,000 or more
8. What is your current marital status
- a. Single, never married
 - b. Married or domestic partnership
 - c. Widowed
 - d. Divorced
 - e. Separated

Appendix B

Support Group Participation and Engagement Questionnaire

1. Have you ever participated in a cancer-related support group?
 - a. Yes
 - b. No
2. How did this support group meet?
 - a. Online
 - b. In-person
 - c. Other:
3. How often did this support group meet?
 - a. Weekly
 - b. Bi-weekly
 - c. Monthly
 - d. As needed
 - e. Other:
4. How long have you engaged with this support group?
 - a. Less than one month
 - b. 1 – 6 months
 - c. 7 months – 1 year
 - d. 1 year and 1 day – 2 years
 - e. Longer than 2 years

Rate to what extent you agree with these statements (regarding your support group):

5. I met other people who had similar experiences to me through this support group.

- a. Strongly agree
 - b. Agree
 - c. Slightly agree
 - d. Neither agree or disagree
 - e. Slightly disagree
 - f. Disagree
 - g. Strongly disagree
6. I felt supported by this support group.
- a. Strongly agree
 - b. Agree
 - c. Slightly agree
 - d. Neither agree or disagree
 - e. Slightly disagree
 - f. Disagree
 - g. Strongly disagree
7. I learned more about the effects of cancer treatment through this support group.
- a. Strongly agree
 - b. Agree
 - c. Slightly agree
 - d. Neither agree or disagree
 - e. Slightly disagree
 - f. Disagree
 - g. Strongly disagree

8. I received/learned about additional resources through this support group.
 - a. Strongly agree
 - b. Agree
 - c. Slightly agree
 - d. Neither agree or disagree
 - e. Slightly disagree
 - f. Disagree
 - g. Strongly disagree