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Correlates of Depressive Symptoms in Adult Survivors of Childhood Cancer

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Abstract

Purpose: The impact of cancer in childhood among adult survivors needs to be studied to see how being diagnosed with cancer in childhood is associated with mental health in adulthood. Specifically this study will examine depressive symptoms. If there are negative effects such as depressive symptoms, it is important to know what may help reduce them such as support and counseling.

Methods: This is a quantitative study where 49 adult survivors of childhood cancer participated in an online survey. They were recruited from forums for cancer survivors and with snowball sampling.

Results: Through correlation analyses and ANCOVA, it was found that counseling helps reduce depressive symptoms in adult survivors of childhood cancer. Other predictors were not found to be significant and would be better assessed with a larger sample.

MONTCLAIR STATE UNIVERSITY

/ CORRELATES OF DEPRESSIVE SYMPTOMS IN ADULT SURVIVORS
OF CHILDHOOD CANCER /

by

Melissa Miller

A Master's Thesis Submitted to the Faculty of

Montclair State University

In Partial Fulfillment of the Requirements

For the Degree of
Master of Arts

May 2016

College of Education and Human Services

Thesis Committee:



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**CORRELATES OF DEPRESSIVE SYMPTOMS IN ADULT SURVIVORS
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Montclair, NJ

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Acknowledgements

I would like to extend my gratitude to my thesis sponsor, Dr. Miriam Linver, for putting so much time into working with me. Over the last nine months there were countless drafts, meetings and a lot of late night editing. Thank you to my committee members, Dr. Dana Heller Levitt and Dr. Pauline Garcia-Reid, for all of your input and time spent contributing to my final product. Thank you to my parents and friends for the encouragement and understanding of the time it takes to complete a thesis. Finally, thank you to all the generous and thoughtful participants for taking the time to complete the survey.

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Introduction

The effects of traumatic childhood life events have been studied over the years, but most researchers have focused only on events such as abuse and violence (Davidson, Devaney, & Spratt, 2010). Few studies have examined how other traumatic childhood events affect adults and if these events may also predict mental illnesses. Specifically, few studies have focused on outcomes of individuals who were diagnosed with childhood cancer to determine if they may be more likely to develop depressive symptoms as adults. There are currently over 300,000 survivors of childhood cancer in the United States (National Cancer Institute, 2014), due to increasing survival rates for childhood cancers. For example, according to The Leukemia and Lymphoma Society, in the 1960's the survival rate for a child with the most common type of childhood Leukemia was less than 20%, whereas now it is more than 90%. Additionally, The National Institute of Health (2012) reports that 16 million adults over 18 (7% of the United States population) have experienced a major depressive episode in the past year. More research needs to be done to investigate the possible link between early traumatic events and adult depressive symptoms, and possible mechanisms to reduce symptoms. It would be ideal to give children with a diagnosis of cancer the best chance at having a healthy adulthood, not

may be because of childhood support received from friends and family and/or counseling. Learning which groups of individuals are more likely to exhibit depressive symptoms may also help mental health professionals to learn more about the at-risk groups and how to better help adult survivors of childhood cancer.

The research literature on childhood cancer diagnosis and links with depressive symptoms and support will be reviewed and Bronfenbrenner's (1977) bioecological model will be used as a framework to help understand adult survivors of childhood cancer and their challenges. Most research on children who have been diagnosed with a serious illness does not have a theoretical context. However, occasionally, theories such as relational autonomy have been used (Howard et al., 2014). The bioecological model is used for the present study because it takes into account all of the systems surrounding a child and how they influence a child's development.

Bioecological Model

Bronfenbrenner's (1977) bioecological model discusses the importance of the systems surrounding an individual (Bronfenbrenner, 1977). Microsystems, macrosystems, mesosystems, exosystems, and chronosystems are the systems that make up Bronfenbrenner's model. In order to describe the relationship between childhood cancer and its effects on depressive symptoms in adulthood, three of the systems will be discussed: microsystems, mesosystems and chronosystems. Figure 1 illustrates the components of Bronfenbrenner's Bioecological Model. More recently, Bronfenbrenner and Morris' (2006) discussion of the bioecological model has taken into account individual characteristics and the importance of the individual in his or her own development. For example, as children get older, their interactions with caregivers

change and children become a larger part of the process of their own learning and development. Children can then use what they have learned to interact with others (Bronfenbrenner & Morris, 2006). Characteristics that emerge later on in a person are a result of the systems that influenced the individual during their early development (Lerner, 2002). Some examples of these systems that are important with childhood cancer patients and survivors include family members, hospitals, schools, mental health professionals, and friends. Development goes both ways in that a person is involved in the learning process and engagement with others and development is not one-sided (Bronfenbrenner & Morris, 2006). The bioecological model can give an accurate picture as to why the systems surrounding a child are so important when he or she is diagnosed with cancer. These systems can determine how a child copes and what support is available.

Bronfenbrenner (1977) describes microsystems as systems surrounding an individual that have a direct effect on that individual. Examples of microsystems for a child are peers, family members, and mental health professionals. These systems may have an effect on a child's psychological functioning. The way a member of a child's microsystem (for example, a caregiver or a friend) handles a child's traumatic situation will have an effect on the child (Polak & Saini, 2015). The characteristics of the individuals in the child's microsystem such as their resources, knowledge, and skills have effects on the child as well (Lerner, 2002). These skills and resources from those in the microsystem are important because depending on their knowledge, skills and resources, a caregiver may be able to provide more or less support for the child. Additionally, the child can use these skills in their interactions with others (Bronfenbrenner & Morris,

2006). When a child is in the hospital or sick, the child can use these learned skills to also cope.

Researchers report that childhood cancer patients struggle with peer relationships because the childhood cancer patients may feel they are missing out on age appropriate activities; thus the peer microsystem is important to consider (Arpawong et al., 2013). This would be more important for adolescents since they depend greatly on their peer networks. Friends may withdraw because they do not know how to talk to a friend who is so sick. The way a child's peers react to their friend's illness can affect how connected children feel with others their age while going through something traumatic. For example, a teenager might miss out on a prom or participating in a graduation ceremony. If teenagers still feel connected and able to spend time with their friends, or even attend events while they are sick, this may influence how they cope and how they feel (Howard et al., 2014; Jacobs & Pucci, 2013; Verhoof et al., 2013). This illustrates how important the peer microsystem is.

The parental microsystem is important because the support of parents may influence a child's own reaction to their diagnosis and influence their coping. The more parental support a child has may mediate the potentially negative effects of a cancer diagnosis and lead to fewer depressive symptoms in adulthood (Howard et al., 2013). A parent's support of a child in the hospital can potentially help to reduce depressive symptoms and lead to healthy coping and psychosocial health. However, parenting styles may change when a family experiences a crisis such as a child developing a serious illness (Polack & Saini, 2015). An older child may be treated like they are younger and their parents may be more overprotective; or illness may cause children to need more

emotional support than is typical at a particular age. The change in parenting style can also affect coping and the relationship between parent and child. For example, as described above, as children get older they may not rely on their parents for support as much as they did when they were in early childhood.

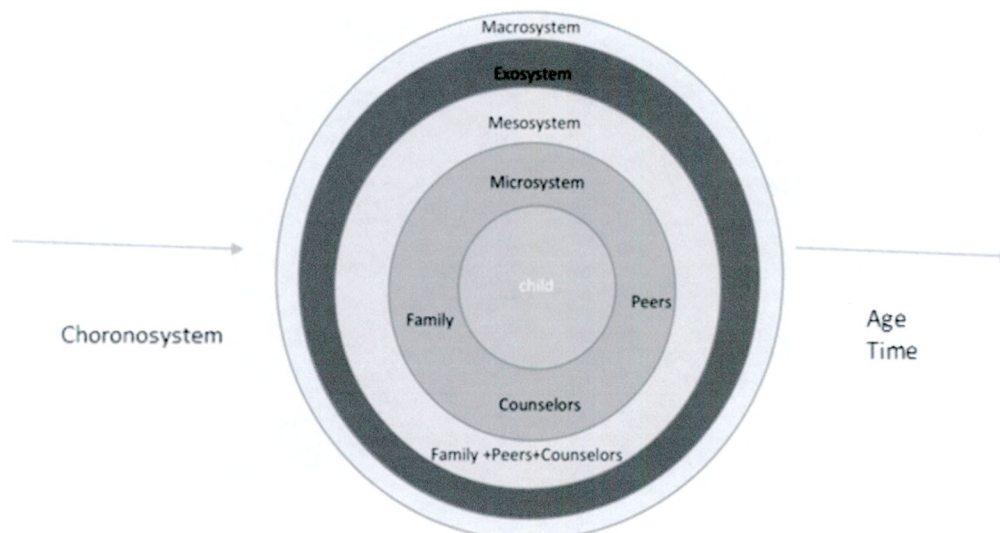
Mesosystems explain how microsystems interact with each other (Bengtson, 2005; Bubol & Sontag, 2004; Lerner, 2002; Polack & Saini, 2015). For example, what happens when a child is in the hospital may affect what happens at home and vice versa. If a child has positive support from family and/or friends, along with counseling, these together may decrease the likelihood of experiencing depressive symptoms in adulthood since mesosystems explain how microsystems interact. Based on the notion that the microsystems can work together to form an effective mesosystem in a child's world, support may be even more effective when parents and therapists collaborate to help the child (Coleman, 2012). This may happen with a plan set in place between the parents and therapist to make sure that there is follow-through at home and in the hospital and to ensure that family members and clinicians are using the same techniques to help the child cope.

Chronosystems are described as time-related dimensions of interaction throughout a person's life (Bengtson, 2005). The interactions between a child and their microsystems may be different depending on the child's age. Children hospitalized for their illness at a young age likely rely almost exclusively on their parents for support while they are young, whereas hospitalized adolescents may rely on both parents and peers. However, teenagers in the hospital may rely more on the support of parents in comparison to their peers, who are relying more on the support of their own friends

(Arpawong, 2013). The age of a child at diagnosis may be a moderating factor in determining whether or not depressive symptoms are present in adulthood. For example, Joubert et al. (2001) found that those who had a body-altering effect, such as a limb amputation, as a result of their disease fared better if it happened at a younger age in childhood because they were able to adjust more easily and had not spent as much of life without knowing anything else. The changes in relationships between children and their parents at different ages illustrates the concept of the chronosystem, which incorporates changes over time within the individual and the system relationships (Bengtson, 2005).

Additionally, the time component of the chronosystem explains how a child going through a cancer diagnosis and treatment may differ at different points in history. For example, as mentioned previously, the prognosis for many cancers would be different in 1960 compared to 1990 compared to 2015. Also, some schools have access to programs now to help classmates understand and help the cancer patient keep up with school and adapt to being back in the classroom. An example of one program like this is the Leukemia and Lymphoma Society's Trish Greene Back to School program (Leukemia and Lymphoma Society, 2016), which not only helps a child return to school, but also helps those systems around a child to better understand how the child may be feeling. However, these types of programs must be available and a school must know about their existence and be willing and able to offer them.

Figure 1: Bronfenbrenner's Bioecological Model



Literature Review

Childhood Illness as a Traumatic Life Event

The existing literature on childhood trauma and adult survivors of childhood cancer will be reviewed next. Variables including, age, formal support, informal support, and gender are examined individually as they may also impact the relationship between childhood cancer and depressive symptoms in adulthood.

Studies of children who were abused or exposed to violence are in agreement that these children are at risk for depressive symptoms as adults (Briggs-Gowan et al., 2010; Davidson et al., 2010; Kliewer, Lepore, Oskin & Johnson, 1998). However, the limited number of studies on adults who had been diagnosed with a traumatic illness as a child

have demonstrated mixed results. Many studies have also measured traumatic childhood events clustered together instead of reporting on each one individually. For example, Pine, Cohen, Johnson, and Brook (2002) and Pirkola et al. (2005) studied a variety of adolescent life events including illness, changes to family structure, and death of a parent; these events predicted future depression and anxiety disorders in both studies. Verhoof, Maurice-Stam, Haymens, and Grootenhuis (2013) found that young adults in the Netherlands with health conditions from childhood were more likely to be depressed if they had to file for disability benefits as adults.

Studies concerning childhood cancer survivors have proliferated recently because over the years, survivorship rates have increased and children are being studied into adulthood for various long-term effects of their treatment(s). The childhood cancer survivor study is an example of the work being done with this group (Brinkman et al., 2013; Zeltzer et al., 2009). A subset of survivors have reported depressive symptoms and other psychological problems (Oancea et al., 2013). For example, researchers report that bone cancer and solid tumor survivors had the worst prognosis regarding psychosocial health because of the serious effects of their treatment and surgery (Arpawong, Oland, Milam, Ruccione, & Meeske, 2013; Wenninger et al., 2013; Zeltzer et al., 2009). Long-term pain, learning or memory problems, and having to file for disability benefits as result of treatment for childhood cancer have been found to increase the likelihood of depressive symptoms in adult survivors of childhood cancer (Brinkman et al., 2013; Oancea et al., 2013). However, many adult survivors of childhood cancer do not currently report depressive symptoms and have the same chance of developing depressive symptoms and mental illness as those in the general population who were not

diagnosed with cancer during their childhoods (Brinkman et al., 2013; Jacobs & Pucci, 2013).

The subset of cancer survivors that do report depressive symptoms needs to be further studied to confirm whether age at diagnosis or the extent of support received through counseling and friends and family play a role in fewer depressive symptoms in adulthood.

Depressive Symptoms

It is important to note that one of the variables in this study will be depressive symptoms not a diagnosis of depression. The fifth edition of the Diagnostic and Statistical Manual of Mental Disorders tell us that the core symptoms of depression are diminished interest in activities and depressed mood most of the day almost every day (American Psychiatric Association, 2013). There are 7 other depressive symptoms including fatigue, insomnia, and feelings of worthlessness. A person can have some of the depressive symptoms and not be diagnosed with major depression. Since a subset of cancer survivors may be more apt to experience psychological side effects, such as depressive symptoms, than the general population, this is an important variable to study. The existing literature on whether depressive symptoms are related to the other variables such as age and gender will be discussed below.

Age at Cancer Diagnosis

Age at diagnosis of childhood cancer may be a factor in determining the likelihood of depressive symptoms in adulthood, but mixed results have been found thus far. The relation of age to cancer diagnosis and depressive symptoms can be examined in multiple ways. Age can be studied by comparing different ages at diagnosis and their

psychological outcomes in adulthood or age can be studied based on current age and number of years since diagnosis. A few studies have examined age in different ways.

Arpawong and colleagues (2013) found that age of diagnosis did not have an effect on post-traumatic growth for children. However, it is important to note that all of the participants in their study were only six months out of treatment and either young adults or adolescents so this result is very preliminary. Wenninger et al. (2013) found that age at diagnosis was not related to negative psychological functioning in adulthood. It has been found that children diagnosed in adolescence as opposed to early childhood were found less likely to be in a romantic relationship as young adults compared to their peers who did not have cancer (Thompson, Marsland, Marhal & Tersak, 2009). This may be related to their peers distancing themselves or perhaps their own insecurities or psychological side effects.

The effects of a body-altering event as a result of cancer may be related to age so this can be classified as examining age at diagnosis. Joubert et al. (2001) suggest that younger children who experienced a body altering event as a result of their cancer fare better psychologically than teenagers who experienced the same or a similar body altering event. An example of a body altering event would be having a limb removed due to bone cancer.

Oancea and colleagues (2013) found that the older respondents in their study had poorer psychological incomes compared to younger respondents. This could be because older respondents, such as those 20 years out from a childhood diagnosis, may have different worries than those who are younger and recently out of treatment. Those worries could include fertility issues as a result of their cancer treatment (Chan et al.,

2013). It is important to study age to find out if different ages at diagnosis requires different psychosocial care and if different points in time post diagnosis require different care as well. For the purposes of this study, early childhood is defined as ages 0-10 and adolescence is defined as ages 11-17. This is because at 18, many are independent from their parents and additionally, different medical centers define patients over 17 in different ways. For example, some hospitals may treat a 19 year old as a pediatric patient while others will treat them as an adult. This may be due to diagnosis, space, or other policies and practices. Since this is hard to quantify, for purposes of this study we will use the legal age of 18 and only look at those diagnosed at age 17 and under.

Formal Support

In this paper, formal support is defined as counseling. Counseling refers to either inpatient or outpatient meetings with a licensed mental health professional. These can include talk therapy or behavioral therapy. Counseling likely helps children who are going through a hospitalization and illnesses and reduces the likelihood of adult depressive symptoms (January, Zablacki, Chan, & Vogel, 2014). This seems likely because positive outcomes have been found when mental health interventions were received by those who experienced other childhood trauma such as violence or abuse (Hodges & Myers, 2010; Kliewer et al. 1998). If counseling brings up traumatic feelings, other wellness approaches with mental health professionals have been effective in enhancing quality of life (Hodges & Myers, 2010). Counseling or mental health interventions, such as cognitive behavioral therapy, have been suggested numerous times for childhood cancer survivors who suffer from depressive symptoms, but no results have been reported (Brinkman et al., 2013; Howard et al., 2014; Wenninger et al., 2013).

Mental health professionals can be better trained on how to work with childhood cancer patients if counseling interventions are shown to be effective.

Informal Support

In this paper, informal support refers to parents/caregivers, friends, and peers. As highlighted in the microsystem discussion, parents can be better informed and trained on how to deal with their child who is sick (Howard et al., 2014). Arpawong and colleagues (2013) reports that adolescents in the hospital rely on parents for support more than other people of the same age who are not going through a traumatic illness. Joubert et al. (2001) found that those who developed side effects from childhood cancer later in life reported more insecure attachments with future partners as an adult than those who developed side effects from their cancer earlier on in life. This could be a result of changes in parenting styles as well.

Peer support is an important factor because children who are in the hospital want to feel like they are still connected to those in their age group and not experience social isolation (Howard et al., 2014; Jacobs & Pucci, 2013; Thompson et al., 2009; Verhoof et al., 2013). Arpawong and colleagues (2013) report that social isolation is the area most childhood cancer survivors struggle with. Again, it must be noted that all of the participants in the Arpawong and colleagues (2013) study were six months out of treatment. However, the experience may be fresh for them as opposed to someone who may not remember as well. Someone who is twenty years out since their diagnosis may not remember exactly how they felt at the time.

The possibility of developing depressive symptoms can happen at any point in the lifespan, so it is important for patients to keep up with long-term care and for them to be

assessed by mental health professionals periodically (Arpawong et al., 2013; Brinkman et al., 2013). Developing depressive symptoms in adulthood could also explain the finding that survivors of childhood cancer who were interviewed at a later age reported more depressive symptoms (Oancea et al., 2013). Howard et al. (2014) report that many childhood cancer survivors feel social isolation later on in life, even if not in childhood. If it is possible to detect the propensity towards depressive symptoms earlier, maybe they can be treated earlier to avoid even more detrimental effects in adulthood. Pine et al. (2002) also note that in the general population, often depression actually begins in adolescence so it is especially important to make sure the necessary support is available while a child is hospitalized.

Gender/Sex

Gender has been found to be a factor in the likelihood of childhood cancer survivors developing depressive symptoms in adulthood as well. Females have been found to demonstrate more depressive symptoms than males (Korkeila et al., 2005). It is interesting to note that since females tend to internalize more, they may need different support and monitoring as the potential effects of being diagnosed with cancer in childhood may not emerge until later (Pirkola et al., 2010; Small, Melnyk, & Sidora-Arcelio, 2009; Wenninger et al., 2013). However, females may be more likely to seek out help based on gender norms. Males may be conditioned to act tough and not seek out help or support (Watts & Borders, 2005).

The constructs that will be examined in this study are gender, age, formal support and informal support among adult survivors of childhood cancer. The goal of the study is to see which of the variables have an effect on depressive symptoms in adult survivors of

childhood cancer. This goal is represented by the following research questions and hypotheses.

Research Questions and Hypotheses

Q1: Does support received during a diagnosis of childhood cancer predict depressive symptoms in adulthood?

H1a: Individuals who experienced a diagnosis of childhood cancer will experience fewer depressive symptoms as adults if they received more parental support as children.

H1b: Individuals who experienced a diagnosis of childhood cancer will experience fewer depressive symptoms as adults if they received counseling in the hospital as children.

H1c: Individuals who experienced a diagnosis of childhood cancer will experience fewer depressive symptoms as adults if they received adequate peer support as children.

Q2: Does current support predict depressive symptoms in adulthood in those who experienced a diagnosis of childhood cancer?

H2a: Individuals who experienced a diagnosis of childhood cancer will experience fewer depressive symptoms as adults if they currently receive adequate familial support.

H2b: Individuals who experienced a diagnosis of childhood cancer will experience fewer depressive symptoms as adults if they currently receive counseling.

H2c: Individuals who experienced a diagnosis of childhood cancer will

experience fewer depressive symptoms as adults if they currently receive adequate peer support.

Q3: Is age of diagnosis associated with depressive symptoms in adulthood for those who have experienced childhood cancer?

H3a: Children who were diagnosed in early childhood will experience fewer depressive symptoms as adults compared to those diagnosed in adolescence.

H3b: Children diagnosed during adolescence will experience more depressive symptoms as adult compared to those diagnosed in early childhood.

Q4: Does gender matter in determining who experiences depressive symptoms in adulthood?

H4: Females will experience more depressive symptoms in adulthood compared to males for those who experienced childhood cancer.

Q5: Are physical side effects associated with more depressive symptoms in adults who have experienced childhood cancer?

H5a: Physical side effects will be associated with more depressive symptoms in adulthood for adults who have experienced childhood cancer.

Q6: Does age of diagnosis moderate the relationship between physical side effects and adult depressive symptoms for those who have experienced childhood cancer?

H6: Physical side effects will be associated with more depressive symptoms in adulthood if the event occurred in adolescence as opposed to early childhood.

Methods

Sample

The sample includes 49 participants over the age of 18 who were hospitalized for childhood cancer at least once when they were under the age of 18. The sample originally included 52 participants, but participants not born in the United States and those diagnosed at age 18 were removed. The sample consists of both males and females who were diagnosed with different types of cancer at various ages 17 and under.

Procedure

Participants were recruited from two online forums for childhood cancer survivors: stupidcancer.org and ihadcancer.com. Additionally, a snowball sampling technique was used, where potential participants were contacted directly by the PI and asked to participate in the survey, as well as to send the survey on to others who may qualify, such as support group members and friends. The participants completed an online survey to measure current depressive symptoms, peer and family support during hospitalizations along with current support, health history (specific cancer diagnosis, physical side effects, psychological side effects, and number of hospitalizations), mental health services received during and after hospitalization, and demographics. The participants were not compensated monetarily. Participants were given access to counseling resources and asked to provide an email address if they wanted to be sent a summary of results upon completion of the study. Email addresses were not linked to survey data. The participants completed an on-line consent form consistent with the consent process for on-line data collection recommended by the Montclair State University IRB. The survey was conducted via Survey Monkey and only the PI and thesis

sponsor have access to the data.

Measures

The measures that were used to address all hypotheses are those for depressive symptoms along with support from family and friends in both childhood and adulthood.

Depressive Symptoms. Depressive symptoms were measured with the patient health questionnaire-9 (PHQ-9). The PHQ-9 is based on the criteria for depression in the DSM IV and consists of 9 questions (Lowe, Unutzer, Callahan, Perkins, & Kroenke, 2004). Participants respond on a scale where 0 indicates not at all and 3 indicates nearly every day. These answers are based on how much the answers are true for the past two weeks (January, Zebracki, Chlan, & Vogel, 2014). A higher total score would mean that a subject demonstrates more depressive symptoms. A PH-Q score greater than 9 indicates depression, however, for this study depressive symptoms were measured (Kroenke, Spitzer, Williams & Lowe, 2010). Depression is a medical diagnosis while depressive symptoms can exist without a diagnosis of depression. Two sample questions are “for the past two weeks, how often have you been bothered by any of the following: feeling down, depressed, or hopeless and feeling bad about yourself-or that you are a failure or have let yourself or your family down” (Kroenke et al., 2010). Construct and criterion validity were found with a study of 6000 participants (Kroenke, Spitzer, & Williams, 2001). Good test-retest reliability and internal reliability were also found with a Cronbach's alpha of .89 (Kroenke et al., 2001). Test-Retest reliability was confirmed in multiple studies with two weeks in between administering the survey (Lowe et al., 2004; Zuthoff et al., 2010). For the sample in this study, Cronbach's alpha was found to be .90; $M=.95$, $SD=.71$. The range was 0-2.89.

Current Support. Current support from family, friends, and special person were measured with the Multidimensional Scale of Perceived Social Support (MSPSS) (Zimet, Dahlem, Zimet, & Farley, 1988). This was relabeled MSPSSN to clarify this scale measures support in the present day (The N was added to indicate “now”). This scale has 12 questions with a 7-point rating scale. 1 indicates very strongly disagree and 7 indicates very strongly agree. Higher scores indicate a greater level of perceived support from family and friends. Zimet et al. (1988) found the the reliability of this scale to be .88 and test-retest reliability was found to be .85 when participants were tested again 2-3 months after the initial survey. Good factorial validity was also found. Some examples of the questions on this scale are “I can talk about my problems with friends” and “I get the emotional help and support I need from my family”. There are questions related specifically to perceived support from friends and questions specifically related to perceived support from family, such that there are separate sub-scales for family support and friends support.

For the current study, the Cronbach’s alpha for the full scale that measured support now was .93; $M= 4.08$ and $SD= 1.30$ and the range was 1-6. For the friends subscale, Cronbach’s alpha was .90; $M=3.93$, $SD=1.53$. The scale ranged from 0-6. For the family subscale, Cronbach’s alpha was .90 and $M= 3.75$, $SD=1.64$. The range was 0-6. Finally, for the special person subscale, Cronbach’s alpha was .94; $M=4.33$, $SD=1.63$. Scores ranged from 0-6.

Support in Childhood. The MSPSS was adapted with permission from the scale’s original author to measure support in childhood and called MSPSSC. The same questions were used to ask participants about past support from family, friends, and

special person such as “ I got the emotional help and support I needed from my family”. The response choices were also the same as in the original scale.

Cronbach’s alpha for this sample for the whole scale that measured support in childhood was .95; $M=4.08$, $SD=1.30$. The range was from 1-6. For the friends scale, Cronbach’s alpha was .97; $M=3.93$, $SD=1.53$, and range was from 0- 6. For the family scale, Cronbach’s alpha was .87; $M=4.44$, $SD=1.30$. The range was from 0.75-6. Finally, for the special person scale, Cronbach’s alpha was .90 ; $M= 4.10$, $SD=1.41$. The range was from 1-6.

Additional measures. Other questions that were included in the survey are demographic questions that assess age at childhood cancer diagnosis, type of cancer, whether the individual has physical side effects, whether or not the individual received formal counseling during childhood (in or out of the hospital) or receives counseling currently, race, current age, number of hospitalizations, education level, marital status, children, where they live, and income. Type of cancer was coded into four categories: brain, blood, bone, and other. Physical side effects and counseling were measured with yes/no choices. The participants were able to expand on the side effects in another open ended question if they chose to do so.

Results

The first step in conducting analyses was to examine the descriptive statistics, including frequencies, ranges, means, and/or standard deviations for all study variables. Table 1 presents the frequencies for all categorical variables. The majority of participants in the present study were single, never married, without children, and had a bachelor’s

degree. Efforts were made to recruit an even number of males and females; however, about three fourths of the study participants were female. The mean age at diagnosis was 10 and evenly divided between 0-10 and 11-17. The number of participants who were unmarried and without children may be due more to the current age of respondents than to the cancer diagnosis, as the majority were under 30. Table 2 presents means, standard deviations, and ranges for continuous variables.

Table 1

Frequencies of Demographic Variables

	N	%
Sex		
Male (0)	10	20.4
Female (1)	29	59.2
Living Area		
Urban (0)	13	26.5
Suburban (1)	22	44.9
Rural (2)	3	6.1
Hospital Counseling		
Yes (0)	20	40.8
No (1)	26	53.1
Outside counseling		
Yes (0)	18	36.7
No (1)	28	57.1
Current counseling		
Yes (0)	14	28.6
No (1)	32	65.3
Physical side effects		
Yes (0)	36	73.5
No (1)	10	20.4
Psychological side effects		
Yes (0)	29	59.2
No (1)	17	34.7

Table 1 (continued)

Ethnicity		
Other (0)	6	12.2
White (1)	27	55.1
Black (2)	1	2
Asian (3)	2	4.1
Hispanic/Latino (4)	3	6.1

Table 2

Descriptives of Continuous Variables

	Min.	Max	Mean	SD
Depressive symptoms (PHQ)	0	2.89	0.95	0.71
Current				
Total scale	1	6	4.08	1.30
MSPSSN family subscale	0	6	3.75	1.634
MSPSSN friends subscale	0	6	3.93	1.53
MSPSSN special person subscale	0	6	4.33	1.63
Childhood				
Total scale	1	6	4.08	1.30
MSPSSC friends subscale	0	6	3.65	1.73
MSPSSC family subscale	0.75	6	4.44	1.34
MSPSSC special person subscale	1	6	4.14	1.41

Next, bivariate correlations were performed to examine the relationships between all variables of interest in the study (e.g. demographic characteristics, study predictors, and study outcomes). Results from these correlation analyses were used to determine which control variables to use in the next set of analyses. Results from correlational analyses were also examined for each pair of predictor/outcome variables in the hypotheses (Table 3).

For the continuous variables in the hypotheses, regression was used. The control variables were selected based on significant correlations. The correlation matrix was examined carefully to find all variables that were correlated with hypothesis variables. For each regression, a series of models was included. In the first model, the dependent variable was regressed on the controls. For regression analyses, the controls that were used were ethnicity, type of cancer, and type of area the participant lived in, depending on which correlations were found to be significant. In the second model, the independent variable was included.

For example, the first hypothesis (H1a), states that children who received adequate parental support in childhood would have fewer depressive symptoms in adulthood. For this hypothesis, the dependent variable is the PHQ scale and the predictor is the family support subscale of the MSPSSC. In the first model the controls were included (the $R^2 \Delta$ for the first model was .15; $p < .05$), and for the second model, the predictor was included (the $R^2 \Delta$ for the second model was .00; *ns*). Therefore, the predictor did not add any meaningful variance to the prediction of depressive symptoms, and the hypothesis was not supported. The process was repeated for all hypotheses that had continuous predictors, specifically hypotheses H1c, H2a, and H2c which

hypothesized that peer support in childhood and peer and family support in adulthood would lead to fewer depressive symptoms in adulthood. For many of these, as seen in H1a, the R^2 was significant for model one, the control variables, but not significant for the next model that included the predictor of interest. The $R^2 \Delta$ statistic for the second model was not significant.

For the hypotheses that included categorical predictors, ANCOVA was used. The controls here were also ethnicity, type of cancer, and type of area the participant lives in. Results from ANCOVA, demonstrated that those who receive counseling currently report fewer depressive symptoms ($p < .05$). Support was not found for any hypotheses except for hypothesis 2b. This hypothesis states that individuals who experienced a diagnosis of childhood cancer will experience fewer depressive symptoms as adults if they currently receive counseling. This is shown in Table 4. This technique was repeated for all the additional hypotheses, but did not yield significant results. The other hypotheses tested whether counseling in the hospital in childhood and physical side effects would lead to more depressive symptoms. The other two that were not significant hypothesized that females and older children would have more depressive symptoms compared to males and younger children.

There is reason to believe that with a larger sample, there would be support for more of the study hypotheses. The moderator hypothesis did not need to be tested since no significance was found. The moderator here was age and whether it made a difference in depressive symptoms in those who experienced physical side effects. In order to test it, there would have needed to be significance in the ANCOVA test for physical side effects and depressive symptoms.

Table 3

Correlation Matrix

	1	2	3	4	5	6	7	8	9	10	11	12	13	14
0.Sex	.22	.10	.17	-.13	-.06	-.11	-.18	.17	.17	.15	.09	.06	.16	.08
1.Age		.08	.05	-.09	-.11	-.32*	-.09	.05	.00	-.08	.08	-.11	.06	-.12
2.PHQ			.06	-.18	-.15	-.21	-.24	-.06	-.11	-.21	.02	-.21	-.05	-.05
3.MSPSSN				-.12	.057	.35*	-.06	1.0**	.89**	.55**	.86**	.63**	.86**	.32*
4.Hospital counseling					.037	.036	.087	-.12	-.13	-.12	-.06	.63**	-.11	-.23
5.Physical side effects						.033	.005	.06	.23	.28	.00	.19	-.14	.03
6.Psych. side effects							.31*	.35*	.37*	.28	.32*	.34*	0.2	-.002
7.Current Counseling								-.1	-.10	.003	-.01	.03	-.03	-.01
8.MSPSSC									.89**	.55**	.86**	.63**	.86**	.32*
9.MSPSSC friends										.64**	.63**	.53**	.64**	.32*
10.MSPSSN friends subscale											.44**	.68**	.31*	.58**
11.MSPSSC family subscale												.72**	.64**	.25
12.MSPSSN family subscale													.40**	.47**
13.MSPSSC special person subscale														.25
14. MSPSSN special person subscale														

Note:**p <.01; *p<.05

Table 4

Analysis of Covariance (ANCOVA) Results for PHQ and Current Counseling Predicting PHQ¹

Source	Type III Sum of Squares	df	Mean Square	F	Partial Eta Squared
		1			
Corrected Model	10.33	0	1.03	2.91**	0.45
Current Counseling (yes/no)	1.55	1	1.55	4.37*	0.11
		3			
Error	12.44	5	0.36		

1. Note: control variables included race, type of area participant lives in, and education.

*p<.005

**p <.001

Discussion

The present study examined adult survivors of childhood cancer using the bioecological framework. The core components of this theory including microsystems, mesosystems and chronosystems guided this study. The sample of adult survivors of childhood cancer age 18 and over was varied in demographic variables such as gender, race, and age. However, the small sample size limited the statistical power, and thus

many of the analyses produced non significant findings. There was only support found for one of the hypotheses. This hypothesis stated that those who currently receive counseling will report fewer depressive symptoms. The other hypotheses that were not supported examined age, gender, and support. It was hypothesized that youth diagnosed at an older age would have more depressive symptoms along with females. Based on Bronfenbrenner's description of microsystems as systems surrounding an individual that have a direct effect on that individual, it would seem that the support of family and friends would influence depressive symptoms. Specifically, it was hypothesized that support in childhood would lead to fewer depressive symptoms in adulthood. The small sample size did not allow this hypothesis to produce significant findings, but in a larger sample it might.

The relationship found between counseling and depressive symptoms stresses the importance of counseling resources being immediately available to survivors of childhood cancer no matter how long it has been since their diagnosis. Fifty-nine percent of participants reported psychological side effects in adulthood, so this is a valid need that should be addressed further. It is interesting to note that more than half the participants did not report receiving counseling currently. It would be interesting to find out if this is because they are not aware of it, do not feel they need it or cannot afford professional mental health services. This illustrates the importance of microsystems (doctors, counselors, parents) working together as mesosystems to make sure survivors are aware of resources available to them.

The bivariate correlation analyses demonstrated how some variables were linked together in the data, hinting at where significant findings may be in future multivariate

analyses with a larger sample. Participants with a Master's degree were less likely to receive counseling than those who did not finish high school while those with a Bachelor's were more likely to receive counseling than those who did not finish high school. It would be interesting to find out why that is the case since it would seem those with more education would be more aware of the availability and importance of using these resources. Additionally, they may be better able to afford mental health services. Perhaps those with more education (Master's level) feel that they do not need the help. Those with a bachelor's degree, however, would also be aware of the resources, but willing to receive the help unlike their counterparts with a Master's degree.

It was also found that those with brain cancer show more depressive symptoms compared to participants who reported other cancer types. This is consistent with past research (Speechly et al., 2006). Brain cancer survivors may have more lasting side effects that can lead to increased emotional distress.

Through correlational analyses, it was found that the participants who were diagnosed in adolescence (age 11-17) were less likely to have psychological side effects compared to participants diagnosed as young children (age 0-10). This is the opposite of what was hypothesized. This could be because the participants who were diagnosed at a younger age have spent longer dealing with the side effects of their cancer or may even still be living with a chronic or recurring cancer compared with those who were diagnosed a few years ago and may be in remission or have no evidence of disease.

A different predictor, gender, did not demonstrate a relationship with depressive symptoms in correlational analyses as was hypothesized in this study and demonstrated in past studies. This may be because there were more females in this study than males.

Also, maybe the females were more likely to be currently receiving help for depressive symptoms because it is more socially acceptable for females to seek help compared to males (Watts & Borders, 2005). The knowledge and resources in one's microsystems have effects on the child so the way the parental system conditions children to believe a certain gender should behave could lead survivors to seek help from a mental health professional (Lerner, 2002).

An important contribution of this study is how the Multidimensional Support Scale (MSSPS) was adapted to be used in a retrospective way. Previously, this scale was only used to assess current support (Canty-Mitchell & Zime, 2000; Stanley, Beck & Zebb, 1998), but for the current study it was adapted for adults to reflect on the support of family, friends, and other close relationships during their childhood. The adapted version of the full scale had good reliability with a Cronbach's alpha of .95. For the friends scale, Cronbach's alpha was .97. For the family scale, Cronbach's alpha was .87 and for the special person scale, Cronbach's alpha was .90.

Additionally, this study examined the use of counseling and support in the past and at present, which had not been done in previous studies. This is important to determine differences in depressive symptoms and at what point support is most important. This can help inform hospitals on what psychosocial care to provide and where to direct patients when they are no longer in treatment. This is a time when many do not know where to go for help.

Future Directions

In continuing this work in the future, it would be important to gather data from a larger sample size in order to have a greater chance of supporting (or refuting) the

hypotheses. Recruitment would be expanded to include in-person recruitment and would take place over a longer time span. Another possibility would be a longitudinal study with follow up years later. This second data point would help to identify when depressive symptoms first occur, or when changes to mental health may happen. I would also modify some of the measures to ask more specific questions about side effects. Then it would be possible to compare different side effects to see which ones have the most negative effects on mental health. There may even be some that lead to positive functioning. Additionally, international participants would be interesting to include because psychosocial care and the value that is placed on it may vary greatly between countries.

Another way to gather more qualitative data would be to hold focus groups with a diverse sample. This would allow for participants to share more about their side effects, the type of treatment they received, and specifically what type of support or counseling they had. It may allow participants to be influenced by one another which could have positive or negative implications. In the section of the survey where participants could expand on their answers, one survivor (Participant 22) said “ I constantly feel separated from my peers. I'm detached and cannot relate to others” and another (Participant 37) stated "I sometimes experience flashbacks to treatment...I often do not have the opportunity to share..." Similar comments were made by other participants as well. These quotes demonstrate how qualitative information is necessary for further understanding what survivors of childhood cancer need.

Another direction that would be beneficial would be to examine further the types of counseling or support from mental health professionals that cancer survivors received.

Having different groups with different types of formal support would help determine which types of support provide better results. For example, a random clinical trial could be used with one group of survivors receiving cognitive-behavioral therapy and another group receiving talk therapy (Davison, Neale, and Kring, 2003; Wampold, 2001).

Cognitive-Behavioral therapy focuses on changing ones thoughts and behaviors while talk therapy is simply verbal (Wampold, 2001). There could be a third control group that did not receive any therapy. Alternatively, a study could compare groups that have previously received these kinds of therapies in childhood.

Limitations

As previously mentioned, the small sample size was a major limitation of this study. Given the hypotheses depended on multivariate regression and ANCOVA analyses, there was not enough power to detect significant findings for the majority of the research questions. The limited sample size was due in part to not having permission to post survey invitations on particular websites and forums that cater to adult survivors of cancer. Another limitation was that the survey also did not take into account that participants may have been taking antidepressants or other medications; these could have been treating symptoms of depression, and therefore reduce some significance levels of analyses that include questions about depressive symptoms.

Conclusion

Studies on adult survivors of childhood cancer are few, but are gaining momentum. These studies show mixed results and more need to be conducted as survivors get older. In the present study, it was found that counseling is effective to reduce depressive symptoms in adult survivors of childhood cancer. Since fifty-nine

percent of respondents reported psychological side effects and three fourths reported physical side effects, this research needs to continue. More research and larger sample sizes could tell us if it is also effective during childhood and what other support is most helpful.

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Appendices

Appendix A: Consent to Adapt the MSPSS

Appendix B: Online Consent Form

Appendix C: Survey

Appendix D: Letter of approval from Montclair State University Institutional Review
Board

Appendix A

Consent to Adapt MSPSS

From: "Zimet, Gregory D" <gzimet@iu.edu>
Date: December 10, 2015 at 3:57:04 PM EST
To: "'millerm38@montclair.edu'" <millerm38@montclair.edu>
Subject: RE: MSPSS

Dear Melissa,

You have my permission to adapt and use the MSPSS in your master's thesis research. I've attached a copy of the scale (with scoring information on the 2nd page) and a document listing several articles that have reported on the psychometric properties of the MSPSS.

Best regards,
Greg Zimet

=====
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Appendix B Online Consent Form

Dear participant,

You are invited to participate in a study of depressive symptoms in adult survivors of childhood cancer. I hope to learn what factors may contribute to depressive symptoms in adult survivors of childhood cancer.

If you decide to participate, please complete the following set of questions. It will take about 30 minutes. You will be asked to answer questions about your health history, current and past support and demographics. You may not directly benefit from this research. However, we hope this research will result in more attention to psychological health in childhood cancer patients.

Any discomfort or inconvenience to you may include sensitive information that may bring up feelings from childhood. If you feel any discomfort during this survey, please call the National Suicide Prevention Hotline at 1800-273-8255 or visit Mental Health America at <http://www.mentalhealthamerica.net/find-affiliate> to find resources in your area. Data will be collected using the Internet. There are no guarantees on the security of data sent on the Internet. Confidentiality will be kept to the degree permitted by the technology used.

If you decide to participate, you are free to stop at any time. You may skip questions you do not want to answer. You may also contact me if you have additional questions at millerm38@montclair.edu. Any questions about your rights may be directed to Dr. Katrina Bulkley, Chair of the Institutional Review Board at Montclair State University at reviewboard@mail.montclair.edu or 973-655-5189.

Thank you for your time.

Sincerely,
Melissa Miller
Master's Student
Family and Child Studies
Montclair State University

By clicking the link below, I confirm that I have read this form and will participate in the project described. Its general purposes, the particulars of involvement, and possible risks and inconveniences have been explained to my satisfaction. I understand that I can discontinue participation at any time. My consent also indicates that I am 18 years of age.

[Please feel free to print a copy of this consent.]

I agree to participate (link to survey). I decline (link to close webpage).

I allow my answers to be used in future research. I decline.

If at anytime during this survey, you feel depressed, call the National Suicide Prevention Hotline at 1800-273-8255.

The study has been approved by the Montclair State University Institutional Review Board as study #00 ____ on _____.

Appendix C

Survey

Adult Survivors of Childhood Cancer**Welcome to My Survey**

Dear participant,

You are invited to participate in a study of depressive symptoms in adult survivors of childhood cancer. I hope to learn what factors may contribute to depressive symptoms in adult survivors of childhood cancer.

If you decide to participate, please complete the following set of questions. It will take about 30 minutes. You will be asked to answer questions about your health history, current and past support and demographics. You may not directly benefit from this research. However, we hope this research will result in more attention to psychological health in childhood cancer patients.

Any discomfort or inconvenience to you may include sensitive information that may bring up feelings from childhood. If you feel any discomfort during this survey, please call the National Suicide Prevention Hotline at 1-800-273-8255 or visit Mental Health America at <http://www.mentalhealthamerica.net/find-affiliate> to find resources in your area. Data will be collected using the Internet. There are no guarantees on the security of data sent on the Internet. Confidentiality will be kept to the degree permitted by the technology used.

If you decide to participate, you are free to stop at any time. You may skip questions you do not want to answer. You may also contact me if you have additional questions at millerm38@montclair.edu.

Any questions about your rights may be directed to Dr. Katrina Bulkley, Chair of the Institutional Review Board at Montclair State University at reviewboard@mail.montclair.edu or 973-655-5189.

Thank you for your time.

Sincerely,
Melissa Miller
Master's Student
Family and Child Studies
Montclair State University

1. Did you receive a cancer diagnosis when you were aged 18 or younger?

yes

no

* 2. By clicking the link below, I confirm that I have read this form and will participate in the project described. Its general purposes, the particulars of involvement, and possible risks and inconveniences have been explained to my satisfaction. I understand that I can discontinue participation at any time. My consent also indicates that I am 18 years of age.

I agree to participate.

I decline to participate.

If at anytime during this survey, you feel depressed, call the National Suicide Prevention Hotline at 1-800-273-8255.

The study has been approved by the Montclair State University Institutional Review Board as study IRB-FY15-16-47 on 1/12/15.

3. My answers can be used in future research.

I agree.

I disagree.

Adult Survivors of Childhood Cancer

Section 1

4. For the past two weeks, how often have you been bothered by any of the following?

	Not at all	Several days	More than half the days	Nearly every day
Little interest or pleasure in doing things	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling down, depressed, or hopeless	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Trouble falling asleep or staying asleep, or sleeping too much	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling tired or having little energy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Poor appetite or overeating	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling bad about yourself-or that you are a failure or have let yourself or your family down	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Trouble concentrating on things such as reading the newspaper or watching tv	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Moving or speaking so slowly that other people could have noticed? Or the opposite-being so fidgety or restless that you have been moving around more than usual	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Thoughts that you would be better off dead or hurting yourself in some way	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

7. How old were you when you were diagnosed with childhood cancer? (please write an age between 0 and 18)

8. What type of cancer were you diagnosed with?

9. Before you turned 18, how many times were you hospitalized for more than 3 days at a time?

- 0-5
- 6-10
- more than 10

10. Did you receive counseling or services from a mental health professional when you were in the hospital as a child?

- yes
- no

11. If you answered yes to question 10, how many times?

- 1-5
- 6-10
- more than 10

12. Did you receive counseling outside the hospital setting when you were a child?

- yes
- no

13. If you answered yes to question 12, how many times?

- 1-5
- 6-10
- more than 10

14. Do you currently receive counseling or other services from a mental health professional?

- yes
- no

15. Are you currently experiencing any physical side effects as a result of cancer treatment when you were under 18?

yes

no

16. If you answered yes to question 15, please describe briefly.

Adult Survivors of Childhood Cancer

Section 4 continued

17. Are you currently experiencing any psychological side effects as a result of cancer treatment you received when you were under 18?

yes

no

18. If you answered yes to question 17, please describe briefly.

Adult Survivors of Childhood Cancer

Section 5

19. What is your month and year of birth? (ex. 01/1980)

20. Gender:

Male

Female

Other (please specify)

21. Ethnicity

- White
- Black
- Asian
- Hispanic or Latino
- Other (please specify)

22. Highest level of education completed

- less than high school
- high school
- bachelors degree
- associates degree
- Master's degree or higher

23. What type of area do you live in?

- urban
- suburban
- rural

24. Are you currently employed?

- yes
- no

25. What is your household income?

- <\$30,000
- \$30,000-\$50,000
- \$50,000-\$75,000
- \$75,000-\$100,000
- >\$100,000

26. How many people currently live in your household?

27. What is your marital status?

- Currently married
- Currently cohabitating
- Single, never married
- Single, divorced
- Single, widowed

28. Do you have children?

- yes
- no

If yes, how many?

29. Were you born in the United States?

- yes
- no

30. Is there anything else you would like to add or any questions you would like to elaborate on?

If you would like to be sent results in the future, please click the following link to provide your email address anonymously: [Email Address](#)

Appendix D

IRB Approval Letter

Dr. Miriam Linver
Montclair State University
Family and Child Studies

Re: IRB Number: **IRB-FY15-16-47**

Project Title: **Correlates of Depressive Symptoms in Adult Survivors of Childhood Cancer**

Dear Dr. Miriam Linver:

After an exempt [2] review, Montclair State University's Institutional Review Board (IRB) approved this protocol on **Jan 12, 2016**.

Although this study is exempt from continuing review, any changes made to this protocol must be submitted as a Study Modification and approved by the IRB.

When you complete your research project you must submit a Project Closure through the Cayuse IRB electronic system.

If you have any questions regarding the IRB requirements, please contact me at [973-655-5189](tel:973-655-5189), cayuseIRB@mail.montclair.edu, or the Institutional Review Board.

Sincerely yours,

Dr. Katrina Bulkley
IRB Chair