

MEMORIES OF ADULT SURVIVORS OF CHILDHOOD CANCER

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A THESIS

Submitted in partial fulfillment of the requirement
for the degree of Master of Science in the
Department of Human Development and Family Studies
in the Graduate School of
The University of Alabama

TUSCALOOSA, ALABAMA

2018

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ABSTRACT

Childhood cancer is a long and intense journey, with many physical and psychological reactions throughout. Childhood cancer survivors recount positive and negative memories about their cancer, including the importance of coping. Coping during childhood cancer has been shown to relate to quality of life after cancer. In this exploratory, qualitative study, we looked more in depth at adult childhood cancer survivors' memories, specifically in relation to diagnosis, coping and life effects of cancer. Participants ($n=27$) were recruited via Amazon's Mechanical Turk (MTurk) and answered a demographic questionnaire and a qualitative survey containing questions about their memories of experiencing childhood cancer. For this study, the questions of interest were: 1: What are adult survivors of childhood cancer memories of initial reactions to cancer?; 2: What are adult survivors of childhood cancer memories of coping during cancer?; and 3: What are adult survivors of childhood cancer reflections of the effects of cancer on the person they are today? Text data were then analyzed using a thematic analysis. In the participants' memories of diagnosis, some important themes emerged, such as a lack of understanding, psychological reactions, a diagnosis story, physical symptoms, and other's reactions. Participants' memories of coping also brought about many common themes, such as maintaining function, support, faith, distraction, and avoidance. Cancer also positively impacted their lives at present, such as being stronger and/or resilient, having a different life outlook and/or attitude, and motivation. These findings indicate that adult survivors of childhood cancer do have strong memories about their cancer diagnosis and coping during their cancer experience, as well as that cancer has an ongoing influence in their life post-recovery.

DEDICATION

This thesis is dedicated to all childhood cancer survivors. Your strength to endure hardship and continue living life to the fullest inspires me each and every day. This thesis is also dedicated to my family. Your never-ending support for me to pursue my passion of child life is something I will always be grateful for.

ACKNOWLEDGMENTS

This thesis would not have been possible without the unwavering support and guidance of Dr. Sherwood Burns-Nader and the Human Development and Family Studies Department at the University of Alabama. I would also like to thank Drs. Deborah Casper and Wanda Burton for the invaluable and insightful help you have offered me throughout this project.

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CHAPTER ONE

LITERATURE REVIEW

Childhood Cancer

Over 10,000 children are diagnosed with childhood cancer each year (Jemal et al., 2009). Some of the most common types are leukemias (blood), brain tumors, Wilm's tumors (kidney), neuroblastomas (nerves), lymphomas (lymph tissue), rhabdomyosarcomas (skeletal), retinoblastomas (eye), and osteosarcomas (bone) (Steen & Mirro, 2000). Fortunately, the survival rate for childhood cancer is high, with the 5-year survival rate exceeding 80% (Lindell et al., 2015). This means a large percentage of children who were once diagnosed with cancer are able to overcome cancer and continue living their lives. To be "cancer free," "cured," or a cancer survivor is a title that is typically given after a certain amount of time, usually 5 or 10 years of "event free" living, meaning the cancer has not returned in any way (Pui et al., 2003). Although the survival rate for childhood cancer is high, it is a long and difficult journey to make it to "survival".

Cancer treatment plans are based on the type and stage of the cancer. Bradwell (2009) explains that are three main ways in which to treat pediatric cancer: surgery, chemotherapy, and radiation. Chemotherapy is the most common treatment plan, but sometimes two or three of these methods are combined. For example, leukemias can typically be treated with only chemotherapy, but solid tumors often involve surgery and radiation (Bradwell, 2009). These treatment plans can also vary greatly in length from about 6 months for Wilms tumor to 3 years for acute lymphoblastic leukemia (Suryanarayan & Marina, 1998; Pui, Relling, Campana, &

Evans, 2002). A common variable in all cancer treatments, though, are the side effects. These include fatigue, pain, nausea and vomiting, weight gain, hair loss, mood changes, and much more (Listenburg et al., 2014).

According to Hakim et al. (2016), infection and complications occur frequently, as chemotherapy treatment wipes out immune systems, putting patients at high risk for other illnesses. Infections also require hospital stays, during which treatment must be stopped, in turn elongating the whole treatment process. These infections can also become serious enough to result in death (Hakim et al., 2016). For those patients who do not respond as well to the typical cancer treatment, especially in the case of a relapse, bone marrow and stem cell transplants are often conducted (Burke, Lindgen, & Verneris, 2012). These are extreme procedures when a donor gives their healthy bone marrow or stem cells to the patient, as theirs are no longer healthy enough to beat the cancer (Meenahagan, Dowling, & Kelly, 2012).

In addition to the physical toll that treatment takes, cancer patients and their families face many other psychosocial difficulties. Some of the most common hardships involve lifestyle changes (Schweitzer, Griffiths, & Yates, 2012). For example, altering one's diet is large part of successful treatment, as treatments lower appetites and the ability to digest certain foods. Patients also learn about foods to avoid due to bacteria to decrease the chance of infection (van Dalen et al., 2016). Many of the same activities previously enjoyed may not be any longer because of the increased possibility of injuries, susceptibility to illness, or lack of energy and interest (Anzar et al., 2006). Changes in families occur as well. For example, Lau et al. (2014) found 27% of families in their study had to relocate for treatment and 13% of parents separated or divorced during their child's treatment. Patients and families also experience financial

problems, such as medical bills due to hospitalizations and changes/lack of parental employment as a result of caring for the ill child (Warner, Kirchoff, Nam, & Fluchel, 2017).

Late Effects

Cancer survivors may continue to experience “late” or “long-term” effects (Lindell et al., 2015). Possible physical side effects that may present themselves long after treatment has ended include heart failure, bone/joint damage, loss of fertility, and secondary cancers (Haddy, Mosher, & Reaman, 2009). The late effects of cancer treatment are not strictly physical though. Many of these late effects are again, psychosocial issues. According to one study, 36% of participants who are adult survivors of childhood cancer experience significant anxiety and/or depression (de Lagge et al., 2016). Some of the most common reasons for anxiety are health related, such as getting another cancer or being able to have children (Zebrack & Chesler, 2001). This is an appropriate feeling as those worries are actual risks associated with the treatments and side effects of cancer (Zebrack & Chesler, 2001). Furthermore, one study found 14% of previous childhood cancer patients who were participants were still struggling with post-traumatic stress, even seven or more years after their cancer diagnosis (Wenninger et al., 2012). Another study by Rourke, Stuber, Hobbie, Kazak (1999) found the most common symptoms of PTSD for previous pediatric cancer patients to be re-experiencing symptoms (i.e., memories, images, nightmares), arousal symptoms (i.e., difficulty sleeping, concentrating, excessive health monitoring), and avoidance symptoms (i.e., staying away from medical sites, refusal to discuss medical history, detachment from friends and family, decreased interest in activities).

One source of anxiety for pediatric cancer survivors is fear of reoccurrence (Simard, Savard, & Hans, 2009). Fear of reoccurrence is the feeling of being fearful that a previous cancer or another cancer may occur again (Koch, Jansen, Brenner, & Arndt, 2013). This is a

common fear for survivors because those who have had a first cancer are more likely to form a new/second cancer (or relapse) than those who have never had cancer (Pui, Campana, & Evans, 2001). In fact, 20% of those with even the most favorable outcomes will relapse (Pui et al., 2001). Therefore, it is not surprising for survivors to fear the potential of cancer coming back into their life. Because of the amount of psychosocial issues that continue to present themselves even after cancer is over, there is a need to continue to address these needs.

Fortunately, there are also positive late-effects of childhood cancer, such as resiliency, more positive outlook on life, and achievement of life goals (Brown, Pearce, Nailey, & Skinner, 2015; Green, Zevon, & Hall, 1990). A study by Brown et al. (2015) found survivors to report three major themes of life after childhood cancer: not being able to “plan out” life, making the most out of life, and helping others. Almost all of the survivors noted that life is unpredictable; therefore, there is no need to spend time worrying about it, but rather spend time enjoying it. Not only did survivors stress the importance of enjoying life, but also to find meaning in the new life they were given. Many considered cancer to have given them their purpose in life, for example, in their employment choice. Finally, the survivors also expressed their love for using their cancer experience to help others who have, are, or will go through the same situation (Brown et al., 2015). While cancer is a great hardship in life, often times, personal growth is the result.

Survivorship

Because there are so many physical and psychosocial late effects, having pediatric cancer can be a lifelong experience. The diagnosis, treatment, and after effects of cancer allow for many memories, positive and negative, to be made. To date, less than a handful of studies have examined pediatric cancer survivors’ memories of cancer. For one, Molinaro and Fletcher

(2017) surveyed 17 participants (10 of which were pediatric cancer survivors and 7 of whom were primary caregivers). They asked the cancer survivors about their memories of the cancer experience and effects they have/are experiencing because of cancer. Almost every survivor seemed to remember their diagnosis, as well as the symptoms that surrounded it. In regards to social support, survivors reported having very supportive peers, while other's reported cruelty and judgment from their peers. They also reported a majority of the time, their families were strong, supportive, and loving, but they were aware of the familial stress their illness caused. While many difficult memories arose for these survivors, almost all reported happy memories as well, such as playing, friendship, community support, and positive treatment news (Molinaro and Fletcher, 2017).

Most recently, Foster et al. (2017) surveyed 47 young adult survivors of childhood cancer. The survivors were asked one broad question, which was to describe anything about their cancer experience. Overall, the survivors felt moved to share about five major themes. These themes were initial reactions to cancer, coping with cancer, social support, effects of cancer experience, and reflections of the cancer experience. For example, in regards to coping, most participants stated play and distraction was the coping technique they most often used. Spirituality was also major theme in coping (Foster et al., 2017). The finding that in one broad question, five themes stood out among cancer survivors suggests the need to further examine adult survivors of childhood cancer's memories of these themes. Further, these themes are obviously important, but the roles that these themes play in the memories of childhood cancer survivors need to be understood more thoroughly.

Coping

Because the cancer experience and the relevant physical and psychosocial difficulties that accompany it are stressful, there is a need to understand coping. Further, psychosocial support can promote coping. For example, psychosocial support promotes self-expression through activities such as journaling (Bass, 2018). A study by Sorgen & Manne, (2002) looked at the coping strategies of children currently undergoing cancer treatment. Problem-based coping was found to be used most often, especially when the stressors were determined to be manageable. Emotion-based coping was utilized less often and when stressors were considered uncontrollable (Sorgen & Manne, 2002). This is important to note because for adult survivors of childhood cancer, coping during childhood cancer is related to quality of life after cancer (Foster et al., 2017). In addition, Compas et al. (2014) found that the use of control coping strategies improves adaptive outcomes for this group (Compas et al., 2014).

Theoretical Framework

According to Lazarus (1984), the theory of cognitive appraisal is a stress and coping model that suggests stress is a dynamic process. The environment produces stressors and then the individual responds to these stressors. The individual's response to the stressor is also a two-step process. Beginning with primary appraisal, an individual assesses the severity of the stressor. In secondary appraisal, the individual determines what resources they have and can utilize in order to deal with the stressor (Lazarus, 1984). This theory has been used to study coping in current childhood cancer patients, as well as current adult cancer patients and adult cancer survivors, but rarely in studying adult survivors of childhood cancer. (Wonghongkul, Moore, Musil, Schneider, & Deimling, 2000; Dowling, Hockenberry, & Gregory, 2003; Balheaves & Long, 1999). In this case, the stressor (childhood cancer) and everything that comes with it should be appraised by the individual, primarily for the severity of the stressor (ex:

slightly stressful, moderately stressful, extremely stressful) and secondarily for the resources (ex: social support, faith, finances, etc.) that can be used to take on the stressor. If the individual can appraise and utilize resources in order to cope well during their cancer experience, there may be adaptive outcomes in survivorship.

Present Study

Childhood cancer is an intense and difficult process, likely creating memories for those who experience it. Molinaro and Fletcher (2017) provided evidence that pediatric cancer survivors have both positive memories, such as quality time spent with family and friends and negative memories, such as the physical pain that occurred before diagnosis and throughout treatment. Foster et al. (2017) provided evidence that initial reactions to cancer, coping with cancer, social support, effects of cancer experience, and reflections of cancer experience stand out as memories survivors recount. Furthermore Compas et al. (2014) and Foster et al. (2017) demonstrate the importance of coping during childhood cancer for later quality of life. The purpose of this exploratory study is to gain a more specific understanding of what adult pediatric cancer survivors remember about their coping during cancer and its influence on the person they are today. In this exploratory study, we hope to answer the following research questions:

RQ1. What are adult survivors of childhood cancer memories of initial reactions to cancer?

RQ2. What are adult survivors of childhood cancer memories of coping during cancer?

RQ3. What are adult survivors of childhood cancer reflections of the effects of cancer on the person they are today?

CHAPTER TWO

METHODS

Participants

A total of 125 childhood cancer survivors were recruited using Amazon Mechanical Turk (MTurk). This is an online system that allows people to take part in numerous research surveys. Inclusion criteria for participants were that they self-identified as 1) having been born and raised in the United States; 2) between the ages of 18-40; and 3) cancer free for five or more years from pediatric cancer. The dataset was cleaned by removing participants who did not meet inclusion criteria. This is, those who did not live in the United States, were under the age of 18 and over the age of 40, did not have cancer, who completed the survey in less than two minutes, or just answered no or other variations. Of the 125 surveys submitted, 17 were deleted due to being viewed by participants, but not taken, being incomplete, or being completed in less than two minutes. This two-minute time limit for exclusion is because the length of the survey and the depth of the questions asked within the survey cannot be completed in a lesser time. Twenty-nine surveys were deleted due to not meeting the inclusion criteria of being between the ages of 18-40, not having pediatric cancer, or being at least five years post treatment. Finally, 17 surveys were auto-approved and 35 surveys were removed for answers that were not applicable. The survey was opened twice in order to ensure that no new themes were emerging. Recruitment then ceased when saturation was reached (when no new themes emerged from the data).

Participant's ($n=27$) ages ranged from 20 years to 39 years old, with an average age of 28.27 years of age. Fifteen men and 12 women participated, with the majority of participants being White (77.8%). Participants' age of diagnosis ranged from 19 months-17 years of age. A majority of participants had Leukemia (59.3%), followed by Lymphoma (22.2%), Brain/Spinal cord (7.4%), Wilm's tumor (3.7) and other (7.4%), one whom had Melanoma and one whom had Heptoblatoma. We did expect though a larger number of leukemia cancers than other cancers because of the higher prevalence and survival rate (Jemal et al., 2009). A majority of participants underwent chemotherapy (96.3%), followed by radiation (29.6%), surgery (25.9%) bone marrow or stem cell transplant (14.8%), and one person whom received target therapy. Of these participants, only three relapsed (11.1%) and one was diagnosed with a secondary cancer (3.7%). See Table 1 for complete demographic/background information. See Table 1.

Table 1. Participant Demographic Frequencies and Percentages

Variable	<i>n</i>	%
Age (M, SD)		28.27; 4.88
Gender (%)		
Male	15	55.6
Female	12	44.4
Race (%)		
White	21	77.8
Black or African American	3	11.1
American Indian	1	3.7
Asian	1	3.7
Other	1	3.7

Ethnicity (%)

Hispanic, Latino, or Spanish origin	2	7.4
Not Hispanic, Latino, or Spanish origin	25	92.6

Education (%)

Some college	9	33.4
Associate degree	5	18.5
Bachelor's degree	9	33.3
Master's degree	2	7.4
Doctorate degree	2	7.4

Marital Status (%)

Single, never married	17	63.0
Married	8	29.6
Divorced	1	3.7
Separated	1	3.7

Employment (%)

Out of work, looking	4	14.8
Student	4	14.8
Working full time	17	63.0
Working part- time	2	7.4
Retired		

Region of US (%)

Northeast	9	33.3
Midwest	5	18.5
South	7	26.0
West	6	22.2

Type of Cancer (%)

Leukemia	16	59.3
Brain/spinal cord	2	7.4
Wilms Tumor	1	3.7
Lymphoma	6	22.2
Other	2	7.4

Age when diagnosed (M, SD)

10.0; 4.22

Type of treatment received (%)

Chemotherapy	26	96.3
Radiation	8	29.6
Surgery	7	25.9
Bone marrow/stem cell transplant	4	14.8
Other	1	3.7

Relapse (%)

Yes		11.1
No		88.9

Secondary cancer (%)

Yes	3	3.7
No	24	96.3

Length of treatment (M, SD)

2.5; 0.58

Years post treatment (M,SD)

16.46; 7.73

Procedure

Institutional Review Board approval was gained before the start of this study.

Participants completed an anonymous Qualtrics survey that was disseminated through MTurk.

Participants read a description of the study “Memories of Adult Survivors of Childhood Cancer.” When participants clicked on this survey link, they were able to read a more descriptive explanation of the study. They provided consent before beginning the survey. The survey took about 30 minutes to complete. Participants were paid .50 cents for their time. This study was funded by my mentor and committee chair, Dr. Sherwood Burn-Nader. No identifying information was gathered, ensuring anonymity of the participants.

Materials

Demographic Survey. The brief demographic survey (see Appendix A) assessed the following: the participant’s age, race, gender, marital status, education/employment status, and diagnosis information.

Memories of Adult Survivors of Childhood Cancer. This survey (see Appendix B) was created for the purpose of this study. This survey was created in collaboration with Dr. Sherwood Burns-Nader, an Assistant Professor at the University of Alabama’s Department of Human Development and Family Studies. As a Certified Child Life Specialist who has been certified by the Association of Child Life Professionals for 11 years, Dr. Burns-Nader’s expertise is in the psychosocial issues of children experiencing healthcare events. She is a preeminent scholar in the child life field who has extensive knowledge on coping, including publications on this topic. Participants were asked questions about family factors, peer factors, diagnosis, treatment, survivorship, important dates, and memories. The survey includes 67 questions that were both quantitative (close-ended) and qualitative (open-ended) in nature. For the purpose of this study, four open ended questions were coded. These questions are 1) “Please write a description of your memory surrounding your diagnosis?” 2) “Please describe your memory of coping during cancer?”; 3) “Please explain why you did or did not cope well during your

treatment?"; and 4) "How did having cancer influence the person you are today?"; These are the four topics that were looked at more in depth in this study. These four questions were examined in order to gain a better understanding of coping and cancer's influence on the person they are today, as previous studies have demonstrated their importance in quality of life after cancer.

Data Analysis

Demographic data was analyzed using SPSS version 23, running descriptive statistic measures. Qualitative data was coded and themes were developed using a thematic analysis. First, the research team individually reviewed data and developed themes. Second, the research team met to discuss domains and came to a consensus about categories. The research team then re-coded the data based on the agreed upon themes. Data was re-coded until a high degree of inter-rater reliability was reached. For the present study, question 1: "Please write a description of your memory surrounding your diagnosis?" was coded to inform research question 1. Questions 2: "Please explain why you did or did not cope well during your treatment?" and 4: "Please describe your memory of coping during cancer?" were coded to investigate research question 2. Finally, question 3: "How did having cancer influence the person you are today?", was analyzed to inform research question 3.

First, the primary researcher individually reviewed each participant's survey responses as a whole. Then, she individually reviewed the responses to the four questions for the present study. This involved reading participant's responses line-by-line to better understand the essence of the data. Two undergraduate research assistants followed the same process. In this phase, specific, one-word descriptors were used, such as "fear," "play," "family," "friends," etc., to determine the most important aspect of the response. Further, notes were taken in order to understand the meaning of the responses.

In the next phase, the research team met to discuss these concepts. These initial domains were grouped into more broad categories. For example, “play” and “activities” became “distraction.” The research team then came to a consensus about initial categories. The research team then coded data based upon the agreed upon coding-schema.

Finally, after themes were finalized, data was re-coded by the research team. Further, a fourth researcher, who had not seen the data or been involved in thematic analysis, coded the data based upon the finalized themes. Data was re-coded until a high degree of inter-rater reliability was reached.

We are confident that saturation was reached, as no new themes emerged from the data. Inter-rater reliability was high between the author and the fourth researcher (89% for question one, 85% for question two, 92% for question three, and 88% for question four). After inter-rater reliability was gathered, the author and the fourth researcher resolved and agreed upon previously differently coded themes.

Representation

This research involves inquiring about and understanding the memories of childhood cancer survivors. It is important that I address my own subjectivity within this subject. I, the author, am a childhood cancer survivor, which is why this field of study is so important to me. While this research is something I am extremely passionate about, I would be remiss not to be transparent as to who I am in regards to this research. My responsibility as a researcher is to eliminate bias as much as possible, which I have taken steps to do. In regards to my emotional bias, I have journaled my own personal thoughts and feelings during the process of analyzing data. Further, I have included direct quotes within this paper, with no alterations, so as to keep the voice of these participants clear and authentic. Finally, the process of thematic analysis that

was used, which involved having other research participants develop themes and code data, was a step that was taken in order to ensure there was as little researcher bias as possible, as well as high inter-rater reliability.

The two undergraduate research assistants are members of the Child Life and Child Development Research Lab, which investigates child development in regards to children undergoing healthcare experiences. Dr. Sherwood Burns-Nader is the advisor of this lab, as well as my graduate school advisor and thesis committee chair.

CHAPTER THREE

RESULTS

Question One. Five major themes emerged from the question “Please write a description of your diagnosis.” The most common themes were people having different psychological reactions to the diagnosis (33%, $n = 9$). The second most common theme was participant’s diagnosis stories (22%, $n = 6$). These were followed by lack of understanding (19%, $n = 5$) other’s reaction to diagnosis (15%, $n = 4$) and physical symptoms (11%, $n = 3$).

Psychological reaction. A general theme was that participants discussed their psychological and emotional reactions to the diagnosis. The most common emotion that arose was fear. Some simply said they were fearful: “What I remember most is fear”, while others gave reasons for their fear: “I thought I was going to die”. Other emotions that were emitted were shock, surprise, confusion, and sadness: “I was told in the exam room what the test results were and I remember just freezing with shock.” Some did not name a specific emotion, but rather recalled, “I had racing thoughts, and thought my life was over.” Though respondent’s recollections were varied, most participants recalled salient emotional responses, like fear, to their diagnosis.

Diagnosis story. Giving a small description of many aspects of the diagnosis was another common theme. Some discussed from the exact moment of diagnosis and beyond:

“I remember sitting in the doctor’s office for my results from the blood tests. My mother and I were waiting anxiously when the doctor came in and told us the news. I was shocked and immediately became depressed among hearing the news. He told us that

had a high chance of survival since they had caught it early. He had suggested a rigorous round of chemotherapy and the prognosis was good. However, the chemotherapy was very difficult and took me about a year to fully recover. Because of my illness I had to take time off of school and was not able to graduate with my class. However I'm grateful for my life but wish I could have those years back.”

Some described events that led up to the moment of diagnosis: “I never wore sunscreen as a child...They quickly diagnosed me with skin cancer”.

Not all parts of diagnosis stories were negative memories:

“It felt like a normal day! It was St. Patrick's day and I had found a bump on my stomach. I just remember everyone around me thought it was a bigger deal than I did. I was never scared or worried of what was to come. I remember my dad left work and met us at the hospital (which meant that it was very serious). Later on that night my grandparents, parents, aunts and uncles met up with us that night at Chuck E. Cheese (it was spring break) and I'm guessing that's when they all talked about it!”

In these diagnosis stories, it is shown that not just one, but many memories of diagnosis were important, from the emotions, to the people around them, to the physical symptoms.

Lack of understanding. Many participants discussed their lack of comprehension about their diagnosis. Some expressed that this lack of knowledge was because they were young: “I was a kid so I really didnt understand it much to be honest my mom would tried to explain it to me and I jsut knew I had to go to the doctors office often for treatments”. Others described simply not knowing much about cancer: “I remember being confused because I didn't know what cancer was”. Regardless of the reasoning, the overwhelming sense of this theme was not having enough information to deal with their cancer diagnosis, therefore, information needs were high.

Other's reactions. Interestingly, some did not discuss their reaction to the diagnosis, but the people's reactions that were around them at the time of diagnosis. Most of these responses were about their family member's reactions, "I remember my mom crying and my whole family sad just sitting in the room"; "How scared my parents were". Another participant discussed the members of the healthcare team, "I remember the friendliness of the hospital staff." This theme portrays that others were often involved in the diagnosis, therefore, were an important part of the memory of a diagnosis of cancer.

Physical symptoms. Some participants remembered the physical symptoms that accompanied the diagnosis. Some simply stated: "It was painful". Other's described their symptoms in more detail:

"I was sick, vomiting a lot. I had lost 10 pounds in a week, just fluids. At that point I was a swimmer for my high school. I was unable to swim even one lap so I knew I was very sick."

Some people's physical symptoms weren't necessarily painful, but rather a change in their body: "I had found a bump on my stomach". Physical symptoms are typical when diagnosed with cancer and it seems that these symptoms are also relevant parts of their memory.

The themes of this first question answer the important question of "what" did the participants remember as being important aspects when diagnosed with cancer. The next question answers the "how" the participants remember dealing with cancer.

Question Two. Four major themes arose from the question "Describe why you think you did or did not cope well?" The most common theme was wishful thinking (40%, $n = 8$). The second most common theme was support by family and friends (35%, $n = 7$). Faith and prayer was the third most common theme (20%, $n = 4$). A few other participants also discussed their lack of

coping (5%, $n = 1$). Seven of these responses were not codable. This is because the respondents gave yes/no answers or their quantitative answer about coping did not match their qualitative answer about coping.

Wishful thinking. This theme represents participants who did what they had to do to get through their illness, without giving specific techniques. Some simply said this in different ways: “I just did the best I could”. Others gave a reason for wanting to get through it: “I had to do what I did. I wanted to get better.” Some responded with doing what they had to do because of their young age and/or lack of understanding, “i was a kid who did not understand so i did my best.” This theme had an essence of wanting to survive, but not knowing how to get through it or being mentally and/or physically tired or trying.

Support. The theme of support was discussed in regards to family and friends. Many discussed their parents: “I stayed strong thanks to my parents”. Other’s discussed their friends: “I remained very close to my friends”. Others discussed both family and friends within their answers, “I think I coped well because I had the support of my classmates and mother to help guide me and push me along the way.” Few participants also discussed support in regards to asking for support when they needed it, “I told people when I was struggling with treatment.” Again, it is evident that other people played a large role in the participant’s process of coping with cancer.

Faith and prayer. A few participants discussed relying on their faith and/or prayers to help them cope: “I just prayed to god that everything would be okay”; “I prayed and wrote in my journal”. Others answers weren’t religious in nature, but had a sense of faith and hope, “I knew it would be ok.” This theme gave the impression of being hopeful, whether this hope was because a specific spirituality/religion or general faith.

Lack of coping. While most participants explained how they believed they coped well, some participants did not believe they coped well. Some people gave reason to their lack of coping, such as lack of understanding (which is a theme in question 1) because of young age, “I didn't really understand what was going on, so it was hard to properly cope.” Other’s discussed their reactions that displayed their lack of coping: “I felt very sick and was very abrasive to everyone around me”. Regardless of if they gave a reason to this lack of coping or not, it is important to note that there were a small portion of participants that struggled with being about to properly cope during cancer.

Overall, these themes addressed the “how” participants dealt with cancer. The next question will acknowledge the question of “why” is cancer diagnosis and coping during cancer important to survivors.

Question Three. Four important themes came from the question, “How did cancer influence your life today?” The most common theme was the feeling of being stronger and/or more resilient (38%, $n = 10$). The second most common theme was having a change of life outlook and/or attitude (35%, $n = 9$). The other two themes were a motivation to do something with their lives (12%, $n = 3$) and cancer having no influence on their life today (15%, $n = 4$). One of these responses were not codable, because of a yes/no answer being given.

Strength and resilience. This theme of strength and resilience was described in regards to being more mentally strong and resilient: “It made me a lot stronger; nothing really gets me down to much”; “It made me strong and made me realize I can do anything”. Interestingly, one participant discussed diverging feelings, “It has made me stronger and at the same time colder.” These feelings of strength and resilience had the sense of being able to face new life stressors more positively.

Change in life outlook/attitude. A majority of participants discussed a newfound perspective on life or change in their personality. Many described the importance of appreciating life: “Live every day as best as I can”; “A lot, it made me realize how delicate life is.”; “I take less for granted.” The idea of this theme was the ability to view life as a whole more positively. Only two of these individuals reported negative changes in their life outlook:

“It made me grumpy and miserable. I did not have a spiritual awakening. In fact it probably made me develop a sour personality for understanding how much pain and suffering can be experienced randomly without warning or comfort to aid you through the process. My high school ex-girlfriend left me and I found out from friends she went to the prom with another man”.

Regardless of whether the change in life outlook was positive or negative, it is evident that cancer had a lasting influence on survivors.

Motivation. This theme was talked about mainly when discussing current or future career paths. One participant said, “Yes, now I’m a nurse”. Another said: “Drove me to want to do cancer research!” Others talked about motivation more generally: “It made me more determined to make something out of my life”. These participants had the intention of using cancer to make meaning and importance out of their lives.

No influence. While a majority of participants said cancer positively influenced their life, very few reported that cancer had no influence: “It doesn't. I've moved past it.” or simply answered no. While only a few participants reported this, it is important to remember that cancer does not affect everyone in a long-lasting way, as people have different reaction to cancer and its effects.

Question Four. Six major themes emerged from the question “Describe your memory of coping during cancer?” The most common theme was using distraction techniques (39%, $n = 9$). The second most common theme was the support of friends and family (30%, $n = 7$). The other themes were faith and prayer (17%, $n = 4$), and avoidance (9%, $n = 2$). Again, a few participants discussed their lack of coping (4%, $n = 1$). Four of these responses were not codable based upon yes/no answers or quantitative and qualitative answers differing.

Distraction: The most common theme of using distraction techniques had many different variations. Play was a common piece of this theme: “I played my game-boy.” Another part of this theme was different activities: “I read a lot of books and watched a lot of movies on my days off to help me cope.” Other mentioned a few ways they used distraction, “I felt like crud pretty often, but I did my best to press on as normal, with the difference being the time I was spending in the hospital. I kept up with hobbies like reading, did as much school work as possible, and just tried to stay positive.” Others spoke about distraction in terms of mindfulness, “I coped by thinking of something else.” This theme encompassed the participants desire to take their minds off of cancer, using a variety of distraction techniques.

Support. Friends and family support was again a major part of the participants coping. Participants spoke positively about their parental support “My parents were always my backbone, they helped me on how to deal with it emotionally”. Others remembered a specific moment in which they felt supported, “i was holding my mom's hand and she was telling me that everything would be alright.” Others mentioned not only strong family support, but friends as well: “Family and friends really helped”. Again, other people, especially family, were a significant part of participant’s coping process.

Faith and prayer. Faith and prayer were again a common theme that emerged when asked about coping. Some discussed their beliefs: “Because I just had peace that God would take care of me”. Others discussed acting upon their faith: “I prayed a lot”. Again, some of these responses were specifically religious, while others were more hopeful in nature.

Avoidance. Instead of engaging in coping strategies and techniques, some participants engaged in avoidance-based coping. Some explicitly noted this: “I remember not wanting to go through chemotherapy and finding an excuse every time to avoid it.” Other talked about things that represented avoidance: “Lots of sleeping”. This theme involved the desire to escape cancer and/or the things that cancer involves, such as treatment and procedures.

Lack of coping. Again, a majority of participants responded that they felt they coped well, but a small few did not feel that they coped properly. One participant reflected on things that they were missing out on: “It was hard not being able to play like I used to all the time.” Another participant described his reaction: “I didn't cope properly; I just cried a lot.” Again, while a small number of participants reported this, it is important to understand that not all participants utilized coping techniques or coped well.

Overall, when reading the responses to the above four questions, along with the remainder of the survey, some of the essence of the responses changed throughout. For example, one participant that spoke positively about the cancer experience throughout the whole survey still reported cancer having an overall negative influence. But, a few participants who spoke negatively about the cancer experience throughout the survey reported a positive influence of cancer in the end.

CHAPTER FOUR

DISCUSSION

Childhood cancer is an extremely challenging process, from the moment of diagnosis to living as a survivor. Previous research has shown that survivors have memories, both positive and negative, about the cancer experience from diagnosis to survivorship (Molinaro & Fletcher, 2017; Foster et al., 2017). Research has also shown the importance of coping during the cancer experience (Compas et al., 2014). This study was conducted in order to learn more about the adults' memories of a childhood cancer diagnosis, coping during childhood cancer, and how childhood cancer influences survivors' lives. We found that childhood cancer survivors remember specific aspects of their diagnosis, specific ways they coped during cancer, and the kind of influence that cancer has had on their life today.

The first research question aimed to understand initial reactions to the cancer diagnosis. The fact that many participants choose to provide a diagnosis story is important because it depicts that not just one, but many aspects surrounding a cancer diagnosis are memorable, from the physical symptoms and emotional reactions of the individual to the environment surrounding them. Interestingly, a "diagnosis story", might be just a chapter in a larger "cancer story". One previous study showed that some patients and families use narratives as a method of talking about their cancer experience, including the moment of diagnosis (Anderson & Martin, 2003). Further, other participants discussed more specific emotional reactions, many of which involved fear or other negative emotions. This supports research about the strong impact of diagnosis,

especially in regards to psychological risk a cancer diagnosis can have on an individual (Caprini & Motta, 2017).

Other participants discussed a lack of understanding about their diagnosis. This was often due to the young age at diagnosis and/or lack of information given to the child about their illness. Within these three primary themes, many had similar secondary themes. For example, some participants reflected on feeling scared because they were too young to understand that they could survive and nobody told them that they would. One way to address this lack of understanding is to provide developmentally appropriate information to children about their diagnosis, prognosis, treatment, among other things according to factors such as age, stage of development, personal preference, and more. One study specifically asked current childhood cancer patients about communication about their cancer and a majority of participants reported that they desired and needed more information about their prognosis, future, social and emotional variables, as well as involvement in medical conversations (Brand, Fasciano, Brand, & Mack, 2017). The medical team, such as a child life specialist, should provide education about diagnosis, procedures, and life with cancer. This is important because providing pediatric patients with developmentally appropriate information has positive outcomes, such as decreased psychological distress (Rushforth, 1999).

The themes that emerged when probing about the initial diagnosis fall in line with the process of primary appraisal, according Lazarus' stress and coping theory. Of course, the cancer diagnosis brings about an increasing amount of stress to the child's life. This intense stress then has to be appraised by each individual. As previously stated, primary appraisal is this assessment of the severity of the stressor (Lazarus, 1984). The themes that emerged here highlight that a patient's primary appraisal of the cancer diagnosis is influenced by

understanding the diagnosis, emotions surrounding the diagnosis, the presence of support during diagnosis, and the physical symptoms that accompany diagnosis. For example, one way the presence of support might affect a child's primary appraisal to a cancer diagnosis is the contagion hypothesis (i.e., parent's emotional state can directly affect the child's emotional state) (Whelan & Kirkby, 2014). Therefore, the way other's reactions can affect the way the participants primarily appraised the stressor of cancer.

Next, the study aimed to understand their memory of coping with cancer. According to the stress and coping theory, finding coping strategies would be the process of secondary appraisal, which is determining the resources that can help you deal with the stress of cancer (Lazarus, 1984). Two questions were coded in order to dig into the process of secondary appraisal during childhood cancer (i.e. "Describe your memory of coping during cancer?" and "Describe why you feel like you did or did not cope well?")

One common thread ran through both of these questions, family and friend's support. The importance of these relationships during the coping process were essential to positive coping, as all participants who had support reported coping well. This "support", while not an exact theme in regards to diagnosis, was evident in that fact that many diagnosis memories involved these people of support. Such findings support the implementation of family-centered care. In the family-centered care model, families are fully informed and actively involved about the child's illness, as well as supported in their psychosocial needs (Holm, Patterson, & Gurney, 2003). Another theme that was found in both questions regarding coping was the importance of faith and prayer, emphasizing the importance of providing spiritual services to cancer patients. Lima et al., (2013) found that when those who believe utilize spiritual coping mechanisms, it brings about a source of comfort and hope, meaning to the disease, and/or peace and acceptance.

Many participants discussed coping well, while not providing specific coping mechanisms. These responses had the impression of just wanting to get through cancer, therefore doing whatever was necessary. Other's talked about specific coping strategies. Some utilized distraction techniques, such as reading, playing, and journaling. Having distraction opportunities, such as play and activities, for childhood cancer patients can reduce pain, fear, and distress (Biermeier, Sjoberg, Dale, Eshelman, & Guzzetta, 2007). The theme of avoidance was also important. This theme supports previous research, which has shown that utilizing avoidant coping style is quite common and can be effective for children with cancer, as well as their parents (Hildenbrand, Alderfer, Deatrck, & Marsac, 2014).

All of these themes are examples of participant's secondary appraisal process, during which they found ways (support, faith, distraction, etc.) to work through the stressor of cancer. While almost all participants reported positively coping, very few reported coping poorly. Some reasons for this lack of coping were lack of understanding and strong psychological reactions. Therefore, the importance of not only helping children understand and process their illness, but also providing effective coping strategies during their illness is essential. Previous research has provided evidence for the benefits of these types of coping strategies. For example, one study found that using distraction, support, and wishful thinking as coping techniques help children manage the side-effects of cancer treatment (Tyc, Mulhern, Jayawardene, & Fairclough, 1995). Foster et al. (2017) provided evidence that childhood cancer survivors do recall these coping attempts during cancer. Further, the use of coping strategies during cancer can relate to the later influence that cancer had on their lives (Compas et al., 2014). These themes continue to support these findings that coping plays a critical role in the cancer experience.

Next, the study examined the influence that cancer has on life after cancer. Many participants reflected on their change in attitudes and life outlooks. These new perspectives included a newfound appreciation for life, taking less for granted, and how to face adversity when it arises. These changes in personality included being more confident, empathetic, and strong willed. Another common theme was the feeling of being more physically and mentally strong and resilient. These themes support the idea of cancer being an experience, that if coped with properly, can have adaptive outcomes later in life, such as positive attitudes and outlooks and strength and resilience. Some participants reported cancer having a direct effect of their life today, most often in career-choice. Because cancer patients spend a great deal of time with medical professionals, these interactions can often influence the survivor's career goals (Bashore & Breyer, 2017). Very few participants reported cancer having no effect on their life today. In previous research, positive coping was found to bring about more positive outcomes later in life (Compas et al., 2014; Foster et al., 2017). For example, Stam, Grootenhuis, Caron, & Last (2006) found that survivors who employed coping strategies, many of which the participants spoke of in our current study, (e.g., support and wishful thinking), reported higher health-related quality of life in adulthood. The current study supports this idea, as many participants that reported using coping strategies also reported cancer having a positive influence on their life during survivorship, which included a high quality of life, especially in regards to the emotional and cognitive domains (mental strength, emotional strength, and positive attitudes/outlooks). Interestingly though, even some who reported a lack of coping during cancer still reported that cancer had a positive influence on their life. These themes highlight the idea that childhood cancer is not a temporary event, but rather has a life-long influence on a person's life.

Overall, these themes support the previous research that childhood cancer survivors have memories surrounding diagnosis, coping, and cancer's influence on their life. This study adds to the current literature by providing more specific information about these memories, such as what aspects of diagnosis were most relevant to each individual, the different types of coping engaged in throughout cancer, and how exactly they felt cancer has influenced their lives today. Further, the themes that emerged from previous research (ex: support) are used to aid with coping in the present study. This study also fills a gap in the literature by using the stress and coping theory in studying survivors of childhood cancer and to support their use of primary appraisal in the diagnosis stage and secondary appraisal to find ways to cope throughout the cancer experience. Further, the cancer experience, which encompasses diagnosis and coping seem to have a, mostly positive, influence on childhood cancer survivor's current lives.

Implications

The intense process of being given a cancer diagnosis, coping through cancer, and living life after cancer, especially during childhood, is important to understand in order to help childhood cancer patients and survivors. Overall, this study showed that most children struggle initially with diagnosis, but many find ways to cope during cancer. Further, childhood cancer seems to have a mostly positive impact on survivors, regardless of reactions to diagnosis and ways they coped. There are, of course, still improvements that can be made in the care of these children, such as providing developmentally appropriate information about diagnosis, providing individual coping strategies, and helping them transition positively to survivorship. One such role in the healthcare setting that is capable of taking on these responsibilities are child life specialists. Child life specialists are professionals whose knowledge is strongly based in child development, specifically in hospital settings. In the hospital setting, they are skilled at

diagnosis education (giving children developmentally appropriate information), provide normalization opportunities that provide for proper coping (through play), and strive to make illness and hospitalization an overall more positive experience. Unfortunately, not all hospitals have access to child life specialists. Most child life programs are found in children's hospitals that reside in large cities or university affiliated hospitals. For example, there are over 4,000 hospitals in the nation that care for pediatric patients, but there are about 400 child life programs (Brown, Ganyard, McCue, & Wilson, 2006). Therefore, promoting child life and child life programs is essential to providing this psychosocial care to all children.

Also, because of the many late-effects, as well as the influence cancer continues to have on a person's life, survivorship clinics could also be beneficial. These are programs that are designed to help children transition from a childhood cancer patient to a childhood cancer survivor, as well as continue to assess the physical and psychological health of childhood cancer survivors (Hudson et al., 2010). Further, involving child life specialists in care of children from diagnosis to survivorship, for example, staffing a child life specialist in these programs, could be beneficial to continuing the provide psychosocial care to cancer survivors.

Future Research

Further research should be done in order to continue to understand this population and these memories that are so important to them. For example, using a different approach to study this population, such as the phenomenological approach. In this approach, data would emerge on its own, such as from an open-ended interview, instead of asking specific questions in survey form. Further, most of the responses in this data were charged with emotion, therefore, studying to valence or emotional load that cancer has on this population would be interesting. Finally, other people and their support to these survivors, was a large part of this data, as it showed up, in

some way, in every question. Therefore, studying the coping of these people, especially family members, would greatly add to the literature, as often children's emotions, stress, and coping can be related to those surrounding them.

Limitations

It is important to note some limitations in this study. One limitation to note is the collection of data through Amazon MTURK. This is a system where people can take surveys in order to make money; therefore, the reliability of these participants may be questioned. Another limitation is that was a retrospective design; therefore, answers can be impacted by memory. Also, a majority of participants were White, non-Hispanic or Latino, therefore, these results cannot be generalized across all races. Further, the Memories of Adult Survivors of Childhood Cancer Survey was created for the purposes of this study and is not currently validated. Finally, it is important to note that the author is a childhood cancer survivor, therefore bias is possible.

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APPENDIX A: DEMOGRAPHIC SURVEY

1. What is your age?
2. What is your gender?
 - Male
 - Female
 - Other _____
3. Are you of Hispanic, Latino, or Spanish origin?
 - Yes
 - No
4. What is your race?
 - White
 - Black or African American
 - American Indian
 - Asian
 - Native Hawaiian or Other Pacific Islander
 - Other _____
5. What is the highest level of education you have completed?
 - No schooling
 - Some high school
 - High school graduate
 - Some college
 - Associate degree
 - Bachelor's degree
 - Masters degree
 - Doctorate degree
6. What is your marital status?
 - Single, never married
 - Married
 - Widowed
 - Divorced
 - Separated
7. Are you currently employed?
 - Out of work, looking
 - Out of work, not looking

- Student
- Self-employed
- Working part time
- Working full time
- Retired

8. What region of the United States do you live in?

- Northeast
- Midwest
- South
- West

9. What type of cancer did you have?

- Leukemia
- Brain/spinal cord
- Neuroblastoma
- Wilms tumor
- Lymphoma
- Rhabdomyosarcoma
- Retinoblastoma
- Osteosarcoma
- Other _____

10. At what age were you diagnosed with cancer?

11. What treatment(s) did you receive? Mark all that apply.

- Chemotherapy
- Radiation
- Surgery
- Bone marrow/stem cell transplant
- Other _____

12. Did you ever relapse?

- Yes
- No

13. Were you ever diagnosed with a secondary cancer?

- Yes
- No

14. How long was your entire treatment process?

15. How many years post treatment are you?

APPENDIX B: MEMORIES OF ADULT SURVIVORS OF CHILDHOOD CANCER

Diagnosis Memories

1. Please write a description of your memory surrounding your diagnosis of cancer.
2. Describe your memory of coping with your cancer diagnosis?
3. Do you remember the moment you were diagnosed?
 - Yes
 - No

If no, skip to question #8

If yes,

4. Where were you when you were diagnosed?
 - Home
 - Hospital
 - Doctor's office
 - Other _____
5. Who gave you the news about your diagnosis?
 - Parents
 - Doctors
 - Another family member
 - Other _____
6. Who was there when you were diagnosed? Mark all that apply.
 - Mom
 - Dad
 - Sibling(s)
 - Other family member
 - Doctor
 - Nurse
 - Other _____
7. What do you do remember feeling/thinking when you were diagnosed?

Family Memories

8. Do you have any siblings?
 - Yes

- No

If no, skip to question #14

If yes,

9. Are your sibling(s)?

- Younger
- Older
- Both

10. Discuss one memory with your sibling(s) during your cancer?

11. How do you think your sibling(s) felt about your cancer?

12. Did your sibling(s) treat you differently during your cancer?

- Yes
- No

If no, skip to question #14

If yes,

13. How did your sibling(s) treat you differently?

14. Did one or both of your parents stay with you during treatment?

- Mom
- Dad
- Both
- Neither

15. Did one or both of your parents continue working during your treatment?

- Mom
- Dad
- Both
- Neither

16. Were you parents together or separated during your treatment?

- Separated
- Together

17. Are you parents currently separated or together?

- Separated
- Together

18. Discuss one memory with your parents during your cancer?

19. Did your parents talk to you about your cancer?

- Yes
- No

If no, skip to question #21

If yes,

20. Please describe what your parents talked to you about in regards to your cancer.

21. Did your parents allow you to ask questions about your cancer?

- Yes
- No

Peer Memories

22. Did your peers understand what your cancer was/meant?

- Yes
- No

23. Please explain why you think your peers did or did not understand your cancer?

24. What kind of support did your peers give you? Mark all that apply.

- Gifts/cards
- Visits
- Calls/texts
- Fundraising
- Inclusion in non-hospitalized activities
- Social media
- Prayer
- Other _____

25. Discuss one memory about your peers during your cancer?

26. Did your peers treat you differently during your cancer?

- Yes
- No

If no, skip to question #28

If yes,

27. How did your peers treat you differently?

28. Did you have friends/peers with cancer/in the hospital at the same time?

- Yes
- No

If no, skip to question #30

If yes,

29. Discuss one memory about/with these friends/peers?

Treatment Memories

30. Please describe your memory of undergoing cancer treatment.

31. Describe your memory of coping during your cancer treatment?

32. What do you remember being the top 3 worst symptoms of treatment?

33. Did you lose your hair?

- Yes
- No

If no, skip to question #35

If yes,

34. What do you remember about losing your hair?

35. Were you ever hospitalized for something other than chemotherapy, such as an infection?

- Yes
- No

If no, skip to question #38

If yes,

36. Why were you put in the hospital?

37. What do you remember about this hospital experience?

38. Did you miss out on any important dates/events because of treatment/hospitalization?

39. What was your best memory of treatment?

40. What was your worst memory of treatment?

41. Do you feel that you coped well during treatment?

- Yes
- No

42. Please explain why you think you did or did not cope well.

43. Which of the following things provided support/help coping? Mark all that apply.

- Doctors
- Nurses

- Child life specialists
- Family
- Peers
- Community
- Play
- Social media
- Support group
- Other _____

Anniversary Memories

44. Are there any days that are still significant to you from your time undergoing cancer, such as the day you were diagnosed or the day you received a special gift? Please explain.

45. Do you remember the exact date you were diagnosed?

- Yes
- No

If no, skip to question #48

If yes,

46. How do you acknowledge this day each year?

47. What thoughts and feelings do you have on this day each year?

48. Do you remember the exact date that you finished treatment?

- Yes
- No

If no, skip to question #51

If yes,

49. How do you acknowledge this day each year?

50. What thoughts and feelings do you have on this day?

51. Do you remember the day you were considered “cancer free” or a “survivor”?

- Yes
- No

If no, skip to question #54

If yes,

52. How do you acknowledge this day each year?

53. What thoughts and feelings do you have on this day?

Survivorship

54. How did having cancer influence the person you are today?
55. Have you/do you ever experience survivor's guilt?

APPENDIX C: IRB CERTIFICATION

THE UNIVERSITY OF
ALABAMA®

Office of the Vice President for
Research & Economic Development
Office for Research Compliance

January 12, 2018

Tori Hinton
Dept. of Human Development & Family Studies
College of Human Environmental Sciences
Box 870160

Re: IRB # 18-OR-014, "Memories of Adult Survivors of Childhood Cancer"

Dear Ms. Hinton:

The University of Alabama Institutional Review Board has granted approval for your proposed research.

Your application has been given expedited approval according to 45 CFR part 46. You have also been granted the requested waiver of written documentation of informed consent. Approval has been given under expedited review category 7 as outlined below:

(7) Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

Your application will expire on January 10, 2019. If your research will continue beyond this date, please complete the relevant portions of the IRB Renewal Application. If you wish to modify the application, please complete the Modification of an Approved Protocol form. Changes in this study cannot be initiated without IRB approval, except when necessary to eliminate apparent immediate hazards to participants. When the study closes, please complete the Request for Study Closure form.

Should you need to submit any further correspondence regarding this proposal, please include the above application number.

Good luck with your research.

Sincerely,

~~Director & Research Compliance Officer~~
~~Office for Research Compliance~~