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Tori Hinton- The University of Alabama  
Sherwood Burns-Nader- The University of Alabama  
Deborah Casper- The University of Alabama  
Wanda Burton- The University of Alabama

Deposited 06/07/2024

This is an accepted manuscript published by Taylor and Francis in the Journal of Psychosocial Oncology published February 3, 2022 available at: <https://doi.org/10.1080/07347332.2022.2032530>

Citation of published version:

Hinton, T., Burns-Nader, S., Casper, D., & Burton, W. (2022). Memories of adult survivors of childhood cancer: Diagnosis, coping, and long-term influence of cancer. *Journal of Psychosocial Oncology*, 40(5), 652–665.  
<https://doi.org/10.1080/07347332.2022.2032530>

# Memories of adult survivors of childhood cancer: Diagnosis, coping, and long-term influence of cancer

Tori Hinton, MS, CCLS, Sherwood Burns-Nader, PhD, CCLS, Deborah Casper, PhD and Wanda Burton, PhD

Department of Human Development and Family Studies, The University of Alabama, Tuscaloosa, Alabama, USA; Department of Health Science, The University of Alabama, Tuscaloosa, Alabama, USA

## ABSTRACT

**Purpose:** This study examines adult childhood cancer survivors' memories about diagnosis, coping, and life effects of cancer.

**Research approach:** This qualitative study used inductive content analysis to analyze open-ended responses completed in a survey conducted in 2018.

**Participants:** 27 adult survivors (15 male, 12 female) of childhood cancer, ranging in age from 20–39, who were at least 5 years post treatment.

**Methods:** Participants recruited through Amazon Mechanical Turk responded to a survey which included open-ended questions about experiencing childhood cancer to examine their: (1) memories of initial reactions to cancer; (2) memories of coping during cancer; and (3) reflections of the cancer experience on who they are today.

**Findings:** Inductive content analysis was performed to reveal categories related to the stories shared by participants regarding their memories of childhood cancer experiences. Participants' memories of diagnosis reflected categories such as psychological reactions and family support. Memories of coping reflected themes of family support and distraction. Participants' reported strength and resilience as impacts of cancer on their present lives.

**Implications for Psychosocial Providers:** These findings indicate that survivors of childhood cancer have strong, specific memories about diagnosis and coping during cancer and highlight the potential long-term implications of having cancer. The findings also illustrate the importance of appropriate psychosocial support for childhood cancer patients and survivors.

**KEYWORDS** cancer survivor; childhood cancer; coping; diagnosis; late-effects; memories

## Introduction

Approximately 11,060 children are diagnosed with cancer each year in the United States.<sup>1</sup> When patients and families receive a cancer diagnosis, they experience many stressors, such as uncertainty of prognosis, side-effects of treatment, financial burden, and changes in family dynamics.<sup>2-5</sup> One study that interviewed parents of childhood cancer patients revealed that the diagnosis of cancer commemorated a pivotal moment, the adaption of their life to include the care of a child with a serious illness (Griffiths and Yates 2011). Another study interviewed cancer patients themselves, who reported that some notable aspects of living with cancer include decreased physical function, body image issues, isolation (e.g. long hospital stays), and facing one's own mortality.<sup>6</sup>

Survivorship is a meaningful milestone, and fortunately, the 5-year survival rate of childhood cancer exceeds 80%.<sup>1</sup> Despite the difficulty of a cancer experience, some survivors experience positive effects of cancer, such as familial closeness, self-awareness, and desire to help others.<sup>7,8</sup> Other research suggests though, that many survivors may continue to deal with stressors and late-effects of cancer beyond treatment. For example, studies show that survivors may still struggle with increased anxiety, low self-esteem, behavioral problems, and other aspects of psychosocial well-being.<sup>9</sup>

Because there are physical and psychosocial late effects, having pediatric cancer can be a lifelong experience. The diagnosis, treatment, and long-term 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. Molinaro and Fletcher<sup>10</sup> provided evidence that pediatric cancer survivors have both positive memories, such as quality time spent

with family and friends and negative memories, physical pain that occurred before diagnosis and throughout treatment. Foster et al.<sup>11</sup> 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.<sup>12</sup> and Foster et al.<sup>11</sup> Findings from studies have demonstrated the importance of coping during childhood cancer for later quality of life.

Because the cancer experience and the relevant physical and psychosocial difficulties that accompany it are stressful, there is a need to understand coping. A study by Sorgen and Manne<sup>13</sup> 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<sup>12</sup>. This is important to note because for adult survivors of childhood cancer, coping during childhood cancer is related to quality of life after cancer.<sup>11</sup> The use of control coping strategies, in particular, was found to improve adaptive outcomes for this group.<sup>12</sup>

According to Lazarus and Folkman's stress and coping theory,<sup>14</sup> when stress occurs, people determine the difficulty of the stressor (primary appraisal) and what resources they have to cope with the stressor (secondary appraisal). When children and families are experiencing the diagnosis and treatment of pediatric cancer, they engage in primary and secondary appraisal. By better understanding the stressors and needed coping resources, the healthcare team may be able to address the psychosocial care needs of patients with pediatric cancer.

This study aims to add to the existing literature by investigating in-depth facets of survivors' memories of diagnosis and coping during treatment, as well as to determine how the past cancer experience has shaped their current lives by examining the following research

questions: (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) How do adult survivors of childhood cancer think cancer affected the person they are today?

## **Methods**

This survey study utilized open-ended questions to gather data about adult survivors' memories of childhood cancer. Results of the open-ended survey responses were then analyzed using inductive content analysis.

### ***Data collection***

Participants were recruited through Amazon Mechanical Turk (MTURK). The research team provided participants a description of the study and an electronic consent form. Participants for this study responded to open ended survey questions, in addition to demographic and background questions. The survey took approximately 30 minutes to complete and participants were paid 50 cents for taking part in the survey. No identifying information was gathered, ensuring anonymity. This study was approved by the Institutional Review Board at The University of Alabama.

The survey included 60 open and closed-ended questions (30 each) about memories related to family, peers, diagnosis, treatment, and survivorship. The survey was created by two Certified Child Life Specialists (CCLS), the primary and secondary authors. Each contributed specific knowledge and experience to survey development. The survey questions were based on their training and experience, as well as empirical based knowledge from psychosocial literature. For example, one item was: "Did your parents talk to you about your cancer?" This item was a

part of the survey because, while it is important for children to have developmentally appropriate information about their diagnosis, parents often find this task overwhelming.<sup>15</sup> The survey asked closed-ended questions such as “Do you remember the moment you were diagnosed with cancer?,” as well as open-ended questions, such as “Please write a description of your memory of your diagnosis” to gain deeper insight into participants responses.

The current study is a part of a larger study that asked adult survivors of childhood cancer to reflect on their memories of specific topics, including diagnosis, coping during cancer, parent and sibling relationships, peer relationships, milestone celebrations, and adult survivorship.<sup>16</sup> To address the research questions for this study, the following three open-ended questions were analyzed: (1) “Please write a description of your memory surrounding your diagnosis,” (2) “Please describe your memory of coping during cancer,” and (3) “How did having cancer influence the person you are today?”

### ***Data analysis***

Descriptive statistics of demographic information were conducted using SPSS version 25. Inductive content analysis was used to code the narrative responses and develop broader meaning categories. Given that the narrative responses to the survey were provided in written text, content analysis was appropriate for the purpose of making inferences about the stories shared.<sup>16</sup> Content analysis is a research tool used to quantify and analyze the presence of certain concepts within types of qualitative data, including written text.<sup>17</sup>

The primary author and two research assistants independently reviewed the participant responses using a descriptive coding technique, then summary codes were written while reading each response.<sup>18</sup> In this first phase, codes were freely developed. For example, “My parents were

always my backbone” included notes such as, “parents were support.” The next phase included pattern coding, or the grouping of codes that are similar in concept.<sup>18</sup> For example, “parents were support system” and “friends gave me support” became “support.” A co-investigator, who had not seen the data or been involved in the analysis, then coded the data based upon the finalized codes. Inter-rater reliability was high between the primary investigator and the reliability coder (89% for question one, 92% for question two and 88% for question three).

## **Results**

### ***Participants***

A total of 125 people were recruited using MTURK, an online system that allows people to take research surveys. Participants are shown a list of surveys they are qualified to answer, based upon eligibility requirements determined by MTURK. Further inclusion criteria, created by the research team, required participants to self-identify as being: (1) born and raised in the United States, (2) between the ages of 18–40 years, 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 ( $n = 29$ ), completed the survey in less than two minutes, ( $n = 34$ ), or answered yes/ no to questions requiring narrative responses ( $n=35$ ). Ninety-eight surveys were removed, creating a sample size of 27. Fifteen males and 12 females completed the survey. Participants ( $n=27$ ) ages ranged from 20 years to 39 years old ( $m = 28$ ,  $sd = 4.88$ ). 77.8% were white, 11% were black or African American, 3.7% were Asian American, 3.7% were American Indian, and 3.7% were another race. Participants diagnoses included leukemia (59.3%), lymphoma (22.2%), brain tumors (7.4%), Wilms tumor (3.7) and other (hepatoblastoma and skin cancer) (7.4%). See Table 1 for further demographic information.

## ***Diagnosis***

Table 2 presents the codes for the three categories, namely diagnosis, coping, and survivorship. Five codes emerged from the question “Please write a description of your diagnosis.” The most common code was psychological reactions (33%). The second most common code was participant’s diagnosis stories (22%), followed by lack of understanding (19%), other’s reaction to diagnosis (15%), and physical symptoms (11%).

***Psychological reaction.*** The most common response to diagnosis memories was psychological/emotional reactions to diagnosis (33%). The most common emotion noted was fear. For example, the fear of the prognosis, “I thought I was going to die” (dx age 15; 27 years). Other emotions that were emitted were surprise and sadness, “I was told in the exam room what the test results were and I remember just freezing with shock” (dx age 15; 28 years).

***Diagnosis story.*** Giving a description about many aspects of their diagnosis was another common response (22%). Some discussed 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 [...] He told us that had a high chance of survival since they had caught it early [...] Because of my illness I had to take time off school and was not able to graduate with my class. I’m grateful for my life, but wish I could have those years back. (dx: age 12; 34 years)

Some described events that led up to diagnosis, “I never wore sunscreen as a child...they quickly diagnosed me with skin cancer” (dx: age 9; 30 years). Not all parts of diagnosis stories were negative:



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. (dx: age 4; 25 years)

***Lack of understanding.*** Participants (19%) also discussed 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 didn't understand it much to be honest; my mom would tried to explain it to me and I just knew I had to go to the doctor's office often for treatments" (dx: age 7; 29years). Others described not knowing anything about cancer, "I remember being confused because I didn't know what cancer was" (dx: age 5; 22 years).

***Other's reactions.*** Several participants (15%) reflected on others' reactions to the diagnosis. Most responses were about their family member's reactions, "I remember my mom crying" (dx: age 6; 22 years). Another participant discussed the members of the healthcare team, "I remember the friendliness of the hospital staff" (dx: age 17; 22 years).

***Physical symptoms.*** A few participants (11%) remembered the physical symptoms that accompanied 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. (dx: age 15; 30 years)

### ***Coping***

Three codes emerged from the question, "Describe your memory of coping during cancer?" The three codes were distraction (35%), support (27%), and faith and prayer (15%).

**Table 1.** Demographics.

<i>Characteristic</i>	<i>n</i>	<i>%</i>
Gender		
<b>Male</b>	15	55.6
Female	12	<b>44.4</b>
Race		
White	21	77.8
Black or African American	3	11.1
American Indian		3.7
<b>Asian</b>		3.7
Other		3.7
Ethnicity		
Hispanic, Latino, or Spanish origin	2	7.41
Non-Hispanic	25	92.6
Marital status		
Never married	17	63.0
Married	8	29.6
Divorced		3.7
<b>Separated</b>		3.8
Education level		
Some college	9	33.3
Associate <i>degree</i>	5	18.5
Bachelor's degree	9	33.3
Master's degree	2	7.41
Doctoral degree	2	7.41
Employment		
Out of work, looking	4	<b>14.8</b>
Student	4	<b>14.8</b>
Working part-time	2	7.41
Working full-time	17	63.0
Region of US		
Northwest	9	33.3
Mideast	5	18.5
South	7	25.9
West	<b>6</b>	22.2
Type of cancer		
Leukemia	16	59.2
Lymphoma	<b>6</b>	22.2
<b>Brain tumor</b>	2	7.4
Wilms tumor		3.7
Hepatoblastoma		3.7
Skin cancer		3.7
Treatment		
Chemotherapy	26	56.5
Radiation	8	17.4
Surgery	7	15.2
Bone marrow transplant	4	8.7
Targeted therapy	1	3.7
<b>Recurrence</b>		
Yes	3	11.1
No	24	88.9
Secondary cancer		
Yes	1	3.7
No	26	96.3
Age (28.27 ± 4.87years).		

**Table 2.** Codebook.

<i>Category</i>	<i>Code</i>	<i>Description</i>	<i>n</i>
Diagnosis	Psychological reaction	Any thought, feeling, emotion arising from the mind about diagnosis	9
	Diagnosis story	Discussing multiple aspects of memories about diagnosis	6
	Lack of understanding	Lack of knowledge and/or information about cancer and/or hospitalization	5
	Other's reactions	Discussing memories of other people's reactions to their diagnosis rather than one's own reaction	4
	Physical symptoms	Discussing the physical symptoms of cancer leading up to and/or at diagnosis	3
Coping	Distraction	Distracting mind and/or body from anything related to cancer (i.e.: treatment, side effects, etc.)	9
	Support	Friends, family, and others providing emotional and/or physical support	7
	Faith/prayer	The act of requesting help from and/or belief in someone or something	4
Survivorship	Strength/Resilience	Ability to face and recover from difficulties after cancer experience	10
	Change in life outlook/attitude	Mindset shift after cancer experience	9
	Motivation	Emphasizing cancer as the reason for acting in some way	3

***Distraction.*** The most common mechanism of coping remembered by participants was distraction techniques (35%). Play was a common distraction technique reported, “I played my game-boy” (dx age 5; 22 years). Participants engaged in other activities too, “I read a lot of books and watched a lot of movies to help me cope” (dx age 12; 34 years). Another mentioned maintain usual activities, “I kept up with hobbies like reading and did as much schoolwork as possible” (dx age 17; 22 years).

***Support.*** Twenty-seven percent of participants reported family and friends support were beneficial to their coping. Participants spoke positively about their parental support, “My parents were always my backbone, they helped me on how to deal with it emotionally” (dx age 10; 21 years). 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” (dx age 9; 30 years).

***Faith and prayer.*** Participants (15%) noted faith and prayer as a coping mechanism. Some discussed their beliefs, “Because I just had peace that God would take care of me” (dx age 15; 28 years). Others discussed acting upon their faith, “I prayed a lot” (dx age 5; 30 years).

### ***Survivorship***

Three codes emerged from the question, “How did cancer influence your life today?” The three codes were strength and resilience (38%), change of life outlook and/or attitude (35%), and motivation to do something with their lives (12%). One response was not codable because of yes/no answer on this specific question only.

***Strength and resilience.*** The most common code was that cancer made survivors mentally stronger and more resilient (38%). One participant voiced, “It made me a lot stronger; nothing really gets me down too much” (dx age 6; 22 years).

***Change in life outlook/attitude.*** Many participants (35%) also discussed a newfound perspective on life. Most were positive perspective changes, “A lot, it made me realize how delicate life is” (dx age 10; 21 years). Only two of these individuals reported negative changes in their life outlook. One said:

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. (dx age 8; 25 years)

***Motivation.*** Twelve percent of participants reported cancer motivated them in some way. Some spoke in specifics, such as pursuing a certain career. For example, one participant said, “Drove me to want to do cancer research” (dx age 8; 25years). Others talked about general motivation,

“It made me more determined to make something out of my life” (dx age 15; 30 years). Please see Table 2 for further information about coding categories

## **Discussion**

Childhood cancer is a challenging process mentally, physically, and emotionally, with highs and lows throughout. Because of the impactful and dynamic nature of cancer, previous research has shown that survivors still have memories about their cancer experience.<sup>10</sup> The purpose of this study was to learn more about the impact of a childhood cancer diagnosis, coping during cancer, and how childhood cancer influences people’s lives. The findings show specific aspects of memories about diagnosis and coping, such as participants’ memories of their appraisals of the stressor of cancer. It also shows specific ways in which cancer continues to influence their lives. These findings offer new evidence to enhance the literature as it summarizes the memories that are still salient, highlighting what variables of diagnosis, coping, and life effects of cancer the healthcare team may need to further consider when providing care to this population.

The first research question aimed to understand initial reactions to diagnosis. In the current study, survivors of childhood cancer discussed specific emotional reactions, many of which involved fear and/or other negative emotions. Next, many participants chose to provide a diagnosis story, which depicts that many aspects of diagnosis are memorable, from the physical symptoms to the emotional reactions of individuals surrounding them. Interestingly, a “diagnosis story,” which is providing information about many aspects of their diagnosis, might be a chapter in a larger narrative. One study showed that some patients and families use narratives as a method of discussing aspects of their cancer experience.<sup>19</sup>

Some participants discussed a lack of understanding about their diagnosis. This was often due to young age at diagnosis and/or lack of information. A previous study asked childhood cancer patients about communication preferences regarding their cancer. Most participants reported they wanted and needed more information about their prognosis, social and emotional variables, and desired involvement in medical conversations.<sup>20</sup> Children, even toddlers, can receive honest information about diagnoses and procedures.<sup>21</sup> In fact, such information allows for children and families to better cope with healthcare experiences.<sup>21</sup> For education to be effective, it is crucial that those providing such information assess the patient and family needs and provide individualized information based on the identified needs (Gordon et al. 2021). Psychosocial providers have the education and training to provide diagnostic and procedural information using evidence-based strategies that are play based, resiliency focused, trauma informed, developmentally grounded, relationship oriented, and individualized.<sup>21</sup> Education is valuable and paramount, as patients and families cope more effectively with what is understood and expected, rather than what is uncertain and unpredictable.<sup>21</sup>

Next, the study aimed to understand memories of coping with cancer. Coping is the use of different cognitive or behavioral strategies to adjust to a situation that is viewed as stressful (i.e., demands outweigh available resources).<sup>15</sup> Children's coping is a dynamic process in which they appraise a situation and attempt to implement strategies that meet the demands of the situation.<sup>22</sup> According to Thompson,<sup>15</sup> sometimes the strategies children use allow them to adjust to the demands of that stressful situation (i.e., effective coping). Other times the strategies children use do not allow them to adjust to the demands of that situation (i.e., ineffective coping).

Many of the adult survivors of childhood cancer remembered coping using specific mechanisms. Some reported utilizing distraction techniques, such as playing, reading, and

watching movies. Other research supports the finding that specific distraction opportunities, such as play and journaling, for childhood cancer patients, can reduce fear and distress.<sup>23</sup> Spirituality was another effective coping mechanism discussed, with participants reporting the act of prayer and relying on their faith as instrumental to their coping. This finding emphasizes the importance of providing spiritual services to patients. Another study found that when people utilize their spirituality and/or faith as a coping mechanism, it provides a source of comfort and hope. Participants also discussed family support, including parental presence and emotional support from family, as an effective contributor to coping. Such findings reinforce models of care involving the whole family.<sup>24</sup>

Next, we examined the influence that cancer has on life during survivorship. Many participants reflected on their positive change in life outlook, which involved a shift in perspective about the fragility of life and the importance of “living life to the fullest.” Others discussed the mental strength and resiliency cancer instilled in them, feeling that they could conquer any challenge they might endure. Some participants reported cancer has a direct effect on their life today, most often in career-choice, as some survivors now work in the healthcare/oncology field.

Overall, the current study depicts the difficult journey that is childhood cancer:

- Childhood cancer survivors have many memories of diagnosis and coping, such as processing difficult emotions when diagnosed with cancer, needing additional information, and relying on coping strategies to manage the stressor of cancer.

- Further, for some childhood cancer survivors, the stress of cancer is so impactful, that it has a life-altering influence, such as a shift in one’s perspective about life.

## **Implications for psychosocial oncology**

Due to the intense process of cancer, it is important to understand how to help patients and survivors of childhood cancer. The findings highlight types of support the healthcare team can offer.

- Some participants reported they were too young to understand medical information.

Another finding was that some participants reported they did not have appropriate coping mechanisms. When psychosocial providers provide developmentally appropriate information about diagnosis, provide preparation for procedures, teach coping strategies, and provide the ability to play and develop, children cope better with illness and hospitalization.<sup>21</sup> The healthcare team should include members who are trained to address these psychosocial variables.

- Participants reported a lack of information and the importance of family support, which participants spoke of positively. One way that healthcare providers can meet these needs is by practicing patient and family-centered care. This model is based upon mutual collaborative relationships between medical team, patients, and families, in which patients and families play an active role in healthcare conversations and decisions.<sup>25</sup> By utilizing this approach, patients and families become more involved in care.

- The findings show that cancer influences one's life even after entering survivorship, emphasizing the need for participation in survivorship studies and clinics. These are programs designed to help people transition from cancer patient to survivor. These types of programs give cancer survivors the opportunity to continue to remain vigilant about their physical and mental health regarding the late effects of cancer.

### ***Limitations***



It is important to note some limitations. One limitation is the collection of data through Amazon MTURK. This is a system where people take surveys to make money; therefore, the reliability of these participants may be questioned. This study's sample of participants was predominately Caucasian; therefore, these results cannot be generalized across races. This is also a retrospective study; therefore, the participants' accuracy of memories may have deteriorated. Further, because the participants were not interviewed, there were no qualifying questions asked to gain more clarity. Finally, as this research involves examining memories of childhood cancer survivors, it is important to note that the primary author is a childhood cancer survivor herself; therefore, it is important to address their own objectivity within this study.

### ***Future research***

Further research is needed to continue to learn about adult survivors of childhood cancer. For example, the use of an open-ended design, such as interviewing participants, would allow for follow up questions, providing richer data. Also, support from others was a large part of this data. Therefore, studying the coping of people providing support, especially family members, would add to the literature, as often children's emotions, stress, and coping can be related to those surrounding them<sup>26</sup>

### **Conclusion**

This study provides findings about memories of adult survivors of childhood cancer and adds to the current literature by providing more specific information about the aspects of diagnosis survivors remember, the different types of coping strategies survivors remember using throughout childhood cancer, and the influence cancer has on their survivorship. With information from the present study, the psychosocial team, can offer services that have the

potential to improve the experiences of patients with childhood cancer and help build coping strategies that influence positive long-term outcomes.

## **Acknowledgments**

The authors would like to thank Dr. Sarah Daniels of St. Jude Children's Research Hospital for her assistance with and support of this paper. We would also like to thank Amber Wesoloski, Shannon Anderson and the Child Life and Child Development Research Lab at The University of Alabama for their commitment to this project.

## **Disclosure statement**

No potential conflict of interest was reported by the authors.

## **Funding**

The author(s) reported there is no funding associated with the work featured in this article.

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