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Lived Experiences of Young Adults who had a Sibling with Cancer in Childhood

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Submitted in partial completion of the Master of Arts Degree at Sarah Lawrence College,

August 2019

LIVED EXPERIENCES OF SIBLINGS OF CHILDREN WITH CANCER

Abstract

Childhood cancer affects not only the patient but also the family, including siblings. Often siblings are given less attention and must adapt to drastic life changes in isolation, potentially leading to long-term effects in adulthood. This study explores the influence of childhood cancer on identities of young adults who were children when their siblings were diagnosed with cancer. Ten participants completed semi-structured interviews that described their experiences with childhood cancer as well as their perspectives of the impact it has had on their current lives and identities. Two themes emerged with several subthemes from the 10 participants about the processing of their cancer experiences, including changes related to development and magnitude of impact, and participants' current self-described identities, including increased awareness of mortality and increased empathy. Young adults have varying degrees and kinds of impacts from childhood cancer on their current lives and identities, yet share common themes and characteristics even decades after cancer diagnoses.

Key Words: Childhood Cancer, Siblings, Lived Experiences, Identity, Impact

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Introduction

A childhood diagnosis of cancer is devastating and recognized as such by professionals, family, friends, acquaintances, and even those who have no direct link to childhood cancer. Many will also acknowledge the impact cancer has on a child's family. However, focus on the family often refers to the parents' difficulties and struggles whereas the siblings' experiences go unnoticed. Siblings, though not physically or medically sick, face their own hardships and a cancer story different from other members of the family.

Identity as a Sibling

Before the 1980s, siblings were not often studied or written about in developmental literature aside from the sibling rivalry dynamic and the importance of birth order (Bank & Kahn, 2003). Sigmund Freud, from a large family with many siblings himself, frequently described his theory of mind in terms of the id, ego, and superego through contexts of war and conflict. Life included experiences that caused inner conflict which lead to the development of the ego. Through defense mechanisms, in order to relieve tension, one must navigate the conflict between libidinal and aggressive drives and cultural and social implications. With this conflict-focused mindset and the struggle for parent attention and resources between so many siblings, it is no wonder that Freud originated the theory of sibling rivalry (Freud, 1963). Similar to Freud, Alfred Adler (2009) recognized the conflict between siblings which leads to each assuming their role within the family. He suggested birth order played a role in personality development amongst siblings. While Adler's theory did not receive much scientific support, the general public and parenting media ran with the birth order theory (DeVita-Raeburn, 2004).

While early development theorists focused almost exclusively on the parental influence on child development, later theories began to recognize the significance of other relationships.

However, the introduction of other relationships often included friends or those outside the home, completely bypassing or negating the role of siblings in a child's development. In most theories, siblings seemed to be looped in with friends or anyone after the parents, rather than their own category of relationships. Usually, we have siblings before we have friends. Siblings are not our parents but understand and experience our home life with us.

More recently, there have been several books written specifically about this unique relationship and its dynamics. Bank and Kahn (2003) were inspired to write their book about siblings through their clinical work. During therapy, when patients brought up their relationships with their siblings, Bank and Kahn (2003) admitted to being baffled. They argued this was due in part to their training and the little emphasis that was given to siblings and their influence on identity; sibling and rivalry were synonymous. After much observation and inspection into the world of siblings and after their fifteenth edition, Bank and Kahn conceptualized the sibling bond to be a constant and a source of stability in an ever-changing world. These relationships can be lifelong, define life's journey, hold confidence, offer attachment and solace, and sometimes can be harmful or insignificant (Bank & Kahn, 1997).

Another sibling researcher, Judy Dunn, pointed out the amount of contradictions in the sibling relationship. No two siblings have the same relationship, even within the same family. There can be intimacy beyond most of our other relationships but also much unpleasantness. She acknowledged that the sibling bond counters expectations about relationships (DeVita-Raeburn, 2004). Dunn and Plomin (1990) published more about brothers and sisters but focused on what makes siblings different. While siblings often share genes and live in the same house, Dunn and Plomin point out the many other influences which lead to deviations in personality between siblings. Some of these include different social relationships with classmates and friends,

experiences outside the home, and the treatment from their parents. Most parents aim to stay neutral between their children, but due to each child's needs and gains and fit with the parent, each has a very different parent-child relationship (Dunn & Plomin, 1990). For those who have siblings or those who have observed siblings, it is clear that they hold a connection that is unlike any other that we encounter in our lifetimes. Given the weight of the sibling relationship on a child, it is no surprise that a life experience, such as a having a sibling who has been diagnosed with cancer, profoundly affects numerous aspects of a child's reality.

Influence on Identity Formation

Given the significance and longevity of sibling relationships through life, the presence of siblings in childhood and adolescence can have a major impact on identity development. Siblings have an influence on identity development in adolescence, and birth order and same gender between siblings predict the extent to which identity is impacted (Wong, Branje, Vandervalk, & Hawk, 2009). Additionally, the experience of a trauma and/or chronic illness or diagnoses of one sibling can affect outcomes of other siblings' developmental trajectory and identity formation. While trauma and medical diagnoses are negative experiences, there can be positive outcomes not only for the person affected, but also the siblings. For example, siblings of children with autism acknowledged the challenges of receiving less attention from parents and the difficulty of sharing public spaces with their sibling. However, they also endorsed unconditional love for their sibling with autism and an increased level of acceptance for other people due to their own experiences (Dumpke, 2015). Having continuous interactions with a sibling through childhood affects the self-identity of individuals, which can also be influenced by additional trauma, illness, and loss.

Unique Experience: Having a Sibling with Cancer

Every day, forty-six children are diagnosed with cancer (Cancer, 2016). Many of these children have siblings, sometimes multiple, and there is no denying that childhood cancer is a family diagnosis. However, the impact on siblings is much less recognized than the impact on parents and, therefore, much less attention is brought to and in support of sibling's unique needs.

Not only does a child with a sibling with cancer worry and search for a way to help, but he or she often feels jealousy and guilt (Wilkins & Woodgate, 2005). The sibling experience with cancer is complicated and much different than any other family member. As described previously, having a sibling gives a child a relationship that is unlike any other and defies the expectations of many other connections. When a brother or sister is diagnosed with cancer, the sibling experiences a plethora of emotions, changes in day-to-day routines, and altered life outcomes (Houtzager, Grootenhuis, & Last, 1999).

As a sibling struggles with the news of a cancer diagnosis, many siblings want to be near the family and want to learn more about the child's condition. Especially for young children, when a sibling is not taught what cancer is, how it is treated, or what their sibling will go through, many siblings come to their own conclusions. Many adults, including parents, doctors, and nurses, may assume that the sibling is not listening or does not understand, so they will not directly discuss important cancer topics. However, this leaves the sibling to their own devices and sometimes misinterpretation of important facts. Some children may think it is their fault or that the brother or sister does not want them around anymore. It is important in this shocking and scary situation that siblings are given explanations in age appropriate contexts and opportunities to ask questions about their brother or sister's cancer (Johnson, 1997).

Understandably, parents are overwhelmed when their child receives a cancer diagnosis. Time between job shifts is spent at the hospital, researching their child's cancer type, meeting

with the doctors, coping with their own emotional experience. However, this often leaves the sibling, who is also a child, to be left at home or required to stay with extended family or neighbors. Child developmental theories, while not addressing the specifics of sibling experience with cancer, do emphasize the impacts that having a parent who is preoccupied by other drives or dealing with their own psychological trauma can have on a child's development. Especially for young children, these changes in routine and not having a parent who is present, physically or emotionally, can be predictive of struggles later in life for siblings. For example, Mahler, Pine, and Bergman (2000), assert that infants have a symbiotic relationship with the mother. As children develop, they begin to see themselves as separate from the mother but still wanting to be near her; mom is an important reference point. Given the high reliance on the mother or other parents, the child's development and emotional processing can suffer greatly when the parent is unavailable, physically and emotionally. Alderfer et al. (2009) in a systematic review of literature on siblings of children with cancer found that siblings experience post-traumatic stress symptoms, negative emotional reactions, and lower quality of life in emotional, family and social domains. While these effects are more prevalent closer to diagnosis, challenges still persist beyond two years.

A cancer diagnosis in childhood disrupts not only the child's physical being but also her emotional, social, familial and developmental patterns and trajectories. While healthy siblings do not experience the medical effects of cancer and cancer treatment, several aspects of their lives and development are also greatly affected by a cancer diagnosis. Some siblings have post traumatic responses to their siblings' diagnoses and worry if their siblings will live through treatment (Alderfer, Labay, & Kazak, 2003). Many siblings experience the altering of family roles, often times including less parental interaction, lower parental emotional availability,

staying or living at an extended family's or neighbor's house, and less interaction with their sibling in the hospital. Additionally, the lack of attention and validation that is given to the sibling experience of cancer can further affect emotional responses and stress.

Siblings who are left at home or witness the showering of gifts and attention for their brother or sister can experience feelings of jealousy and sometimes resentment. The focus of the family and most if not all of its energy is directed towards the sick child. In addition, extended family and friends bring gifts, toys, technology, and other surprises for the child with cancer while the sibling observes. Some siblings shy away and internalize their feelings. Some, in need of attention, acknowledgement, and validation, act out or push boundaries. However, because these negative feelings emerge in the midst of having a sibling with cancer, guilt can follow (Johnson, 1997).

Longitudinal Impact of Having a Sibling with Cancer

MacDonald, Patterson, White, Butow, & Bell (2014), following an investigation of unmet needs of children with cancer, explored the longitudinal predictors of psychosocial and emotional distress of adolescent and young adult siblings of cancer patients. Several questionnaires were used to assess siblings' unmet psychological needs. They concluded that unmet needs were more common during treatment and relapse, and increased levels of distress and unmet needs correlated with perceived decrease in quality of relationships with parents. In addition, younger adolescents were more at risk for psychological distress than older siblings. Perceived attention that the sibling received is more predictive of psychological distress than general family functioning or the relationship with their sibling; this creates an opening for possible intervention or protective factors against distress.

In a longitudinal study over 12 months with Taiwanese families, siblings showed more behavior problems and lower social competency when compared to a standardized western population (Wang & Martinson, 1996). In another study, siblings of pediatric cancer patients were more likely to engage in risky drinking behaviors and to be heavy drinkers when compared to a national sample and when compared with cancer survivors (Lown et al., 2012). Risk factors for heavy drinking included being between the ages of 18 and 21, not pursuing higher education or finishing high school, and early age initiation of alcohol consumption. Siblings also showed higher rates of anxiety, global psychiatric distress, and depression, but these did not separate from rates of drinking alcohol (Lown et al., 2012).

Resiliency of Siblings

Many who hear of a cancer story, especially childhood cancer, become overwhelmed with sadness and sympathy, unable to see potential upswings of such a threatening disease. This hope and optimism seem to be harder for outsiders to find than the families with a child with cancer. While no family wishes to go through a child's cancer diagnosis and their stories can be heartbreaking, families who face such adversity can find opportunities for growth and redemption. Murray (1998) collected and analyzed the cancer narrative of one fourteen-year-old sibling. Through her experience, she encountered many of the emotions mentioned previously including anger and guilt. However, the sibling also described opportunities for increased empathy as she recognized others' pain, chances for personal growth to be strong and to find the good, and a desire to help others with the knowledge and expertise she had gained as a sibling of a child with cancer.

In addition, families threatened with the loss of a child to cancer can respond with an even stronger bond and closeness than before the diagnosis (Wilkins & Woodgate, 2005). While

not specifically focusing on siblings, Duran (2013) assessed the positive evaluations survivors of childhood cancer and their families expressed in narratives. Five themes of posttraumatic growth were identified in terms of meaning making, appreciation of life, self-awareness, closeness with the family, and a desire to give back to organizations that helped them and to society in general.

Some parents, whether during or after treatment, come to recognize the exclusive experience of siblings as well as the important roles that siblings fill when family faces crisis and trauma. A mother of a child with special needs wrote a letter to her child with special needs' sibling; the letter was published online. She reiterated the sibling's struggles including witnessing parents taking care of the child with special needs and how siblings are often expected to give this care as well. The mother continued to emphasize that while the sibling experience tests their strength and familial relationships, siblings "will be more prepared for life than anyone else" (Corkern, 2016).

Present Study

While literature on sibling cancer experiences is sparse compared to children with cancer, there are several publications which illustrate the longitudinal impacts of childhood cancer on siblings into adulthood. Most often, mental health and quality of life measures are explored in terms of adult siblings. However, very few studies have explored the sibling experience through direct interviews and narratives, and even less concerning the lived experiences of siblings several years after diagnosis.

This study will add to the limited amount of literature focusing exclusively on the siblings of childhood cancer. This study will focus on the lived experiences of young adults who were children when their siblings were diagnosed with cancer, and more specifically, on their lives and identities today from a self-report, qualitative, narrative description. This study aims to

explore the impact of cancer on young adults several years after a sibling was diagnosed with cancer. While some studies have described the risk factors of siblings for future mental health disorders, substance abuse, and post-traumatic stress, this study will capture the more narrative and direct accounts of siblings without labeling and diagnosing negative responses. Through a strengths-based perspective, this study will shed light on the adaptability of siblings and their lived experiences into young adulthood following the experience of having a sibling with cancer, and some after the death of their siblings.

Methods

Young Adults, 18 years and older, who were children when their sibling was diagnosed with childhood cancer were asked to participate in this study. Participants were recruited through snowball sampling and posts on Facebook (see Appendix A for flyer). Interested participants contacted the researcher, and were then sent an informed consent document (see Appendix B). Participants then returned signed consents to the researcher and orally consented at the time of the interview. Interviews were administered by the researcher through online video chats. Audio recordings captured the interviews, which were then transcribed verbatim and coded. The interviews ranged between 13 and 48 minutes. All study procedures and interview questions were approved by the Sarah Lawrence College Institutional Review Board prior to recruitment.

The semi-structured interview used in this study was modeled after the questions used by Dumke (2015). First, demographic data were collected which included age, gender, racial, cultural, and/or ethnic identities, and spiritual practices. Data concerning the interviewees' family structure were also captured such as the number of siblings in the family and their ages, birth order of both the sibling and the child with cancer, and the interviewee's age at the cancer diagnosis.

The interview was semi-structured with 9 questions. The survey aimed to gather information about the participants' self-identity at the current time, including interests and communities. Information was also collected regarding participants' view of their relationships with other family members as well as a self-reported description of how much effect cancer, and related experiences including the death of a sibling, have had on participants' current identity. Additional data were gathered concerning participants' current or future career and passion endeavors. The interview questions can be found in Appendix C and D.

Participants

A total of 10 siblings participated in this study. Seven of the 10 identified as women, and 3 identified as men. They were 23.3 years old on average and ranged in age from 20 to 28 years. Three of the participants were the first born, 5 were either second or third and had siblings younger than them, and 2 participants were the youngest children in their families. Participants were an average age of 8.2 years when their siblings were diagnosed with cancer, with a range of not being born yet to 15 years old. Six of the 10 participants' siblings have died from cancer. Table 1 provides further description of the study participants.

Analysis

Bracketing

Bracketing is the process by which researchers bring previous experience and knowledge of a research topic into awareness for the purpose of acknowledging biases and presumptions that could affect analysis and reporting (Tufford & Newman, 2012). For this project, the researcher has previous experience working with families affected by childhood cancer. These experiences have informed the researchers' knowledge of and familiarity with the types of challenges these families face, with a particular focus on siblings of children with cancer. Additionally, the researcher has volunteered extensively at a camp for families affected by childhood cancer called Camp Okizu. Because of the short recruitment timeframe and the large population of siblings who were eager to participate in this research who had attended Camp Okizu, the researcher personally knows some of the participants. This relationship could have had effects on the interview process, which were lessened in the analysis portion through transcription and coding. The researcher was aware of the closeness to the research topic and

some of the participants. The researcher followed the interview protocol as written for each participant, regardless of previous acquaintance.

Thematic analysis

A systematic thematic analysis was conducted on the ten interviews. Because this study is focused on siblings' identities and their view of how cancer has influenced their current identities, analysis centered on the participants' current perspectives of influence rather than the events that occurred during their siblings' diagnoses, treatment, and/or deaths. Additionally, family dynamics and relationships were included in thematic analyses only as they related to participants' self-identified characteristics, values, and personalities.

Results

The results of the 10 interviews are categorized into two themes: processing of the cancer experience and current identity snapshots, which are then further detailed into subthemes. Each theme is described to give context and then subthemes are detailed with excerpts from participant interviews. Table 2 shows themes with how many siblings contributed to each theme and subtheme.

Processing, Making Sense of Experience

As participants reflected on their experiences with cancer in childhood, each participant described a process of making sense of their experience and relating it to their current identity. In the time since their siblings were diagnosed with cancer, participants have considered several ways in which they have been affected, as well as changing perspectives as they have become young adults. The subthemes which constitute the larger processing theme are changes in perspective as a result of development, different experience due to loss, the importance of having space to make meaning, and the participants' self-evaluated magnitude of impact.

Changes in perspective as a result of development

Most of the participants (7/10) commented on how their perspective has changed since their sibling was diagnosed with cancer, specifically relating to their lack of understanding as children as well as altering viewpoints as they reach adulthood. Five of the participants, particularly those who had a sibling diagnosed with cancer before they reached 12 years of age, expressed that they had not realized the gravity of a cancer diagnosis in their family until later in their development.

I mean I was 7 so I don't think it really sunk in of what was happening at that time. I mean I knew he was sick and that he had to go to the hospital. But I don't think it

really sunk in until after he went through all the treatments...But I think as an adult I think it was easier to understand.

So I didn't fully understand what it meant that my brother had cancer when he was first diagnosed. I was 8 and I didn't have any experience with anything like that...So going into it I knew that it was something that could kill him but I didn't really grasp the concept of what that meant in my internal world.

Four of the participants also shared that as they aged, and as they reached adulthood, their views about their parents' decisions during their siblings' cancer diagnoses and treatments had changed. Each participant expressed empathy and understanding of how their parents handled the situation at hand. These topics included communication with siblings around diagnosis and treatment, continuation of home life, the shift of attention from siblings to the child with cancer, and decisions to continue or stop treatment.

My parents tried their best to do as much for me and my younger brother but obviously in that kind of situation it turns out to be a little bit more focused on the kid who sick and that's totally fair. I don't blame them at all...I mean looking back my parents definitely did the best that they could, but as a kid I didn't understand that.

I think my parents had to make a lot of difficult choices about whether to continue treatment too when it came to crossroads of what to do. Do we keep trying to cure him with this thing that is totally ruining his body, or do we try to keep him comfortable because we know that the treatment may not even work? So that was really rough. I think my parents were good at knowing if there is a good time, like knowing what the okay time was to let me know things, given my age and maturity...I think if it happened now, I would be way- honestly, now realizing that choices that adults make are no that set in stone like choices that have to be made like that are incredibly difficult and when I was that age that uncertainty was hidden from me, I just thought things were just the way they were.

Different experience due to loss

Six of the 10 participants were bereaved, and each individual commented on how they experience the death or loss of their sibling to cancer today. Several participants commented on the lasting presence of their sibling in their lives even years or decades after the death of their sibling. Participants also commented on their efforts at establishing continuing bonds through continuation of their siblings' interests and hobbies and remaining in contact with people who knew their sibling who passed away. As individuals' lives have changed and moved forward, the bonds that participants share with their siblings change as well.

I think the greatest challenge for myself moving forward is, and it has been for a while, is just kind of figuring out how much I want to let [my brother] be a part of my own identity. Because, don't get me wrong, I love [my brother] and he was a great brother, but at the same point, it's also kind of tough because I want to be my own person. At the same time, I don't want to leave [my brother] behind or completely separate myself from that, because I don't want to do that either.

Three participants also described the painful experiences of bearing witness to their friends' relationships and milestones within their own sibling relationships and the grief that is engendered

I have a void. Just always. Like a shadow about me that's sad...I miss my brother and I wonder -because he would be a freshman in college now so like every milestone is pretty awful. Like his peers all graduating, that was really trippy...I wonder what my brother would be like. And an incredible sense of missing out. Jealousy a bit. But also bigger than jealousy, just disappointment...a big loss, a big gaping hole...Like you can't help but wonder what if it had turned out different...I'll always miss my brother. And wonder what would be different.

For 2 participants, they not only experienced the death of their sibling from cancer, but also, shortly thereafter, went through their parents' divorces. Both individuals reflected on the stress following the death of their sibling and questioned whether their parents could have stayed together if the family did not suffer the loss of a child.

When he first died, that was super hard, super hard, and even the years after, really hard. But then that's also, what came along with my brother dying is, I think, it just created a different family dynamic. So my mom and dad would fight all the time. My dad started drinking a ton; he's an alcoholic. He's sober now but that affected him a lot. So not only was it hard to see my brother die but it also affected the things around in that situation.

Two participants commented on how their perspective of the loss of their sibling has changed since their death. While they share how much they miss their sibling, they also reflected on the strength of their memories during the death and how that time has become a defining time point in their lives. For each of these participants, the experience of a sibling dying in childhood has informed their current identities.

I have a very vivid memory of the night he passed away. I remember it very well and that will always totally stick with me. And it was a very powerful moment. And now when I look back, that memory, like it's not a bad memory, I don't have, like, fear over it and I don't remember being afraid at the time but it's just very potent and very- I can see my brother there and I can smell the things in the room and feel things. It's just a very strong memory I have.

Space to make meaning

Nine of the 10 participants highlighted the importance of having a space to make meaning for themselves around their experience with cancer and some through their bereavement. Seven participants specifically identified what allowed them to find and recreate significance for themselves whether that be through talk therapy, a summer camp specifically for siblings of children with cancer, or creating and contributing in a fundraising nonprofit for cancer research and family support. Two of the participants reflected that they have not yet found a space which

allows processing of their experience and expressed interest in exploring options and strategies for meaning making.

Learning how to talk about difficult things especially through discussion at camp and the example of my friends who had been there longer than me and how they were taught to speak up and share their story made me eventually talk...this is a special sort of healing. I think it taught me just the tools to deal with difficult feelings that result from cancer and losing [my brother] to cancer. It taught me to do difficult feelings and to voice things that are hard that are trapped inside. And not that it's easy to let things go, but at least you feel heard and you can express yourself verbally and still have people want to hug you after is an incredible thing...I've gained emotional intelligence from going to camp and it's allowed me to move forward in my life. And not forget but to deal with things a bit more. Than if I couldn't talk about things.

I think it maybe led to me ignoring emotional issues, but I guess I would need to talk to a counselor or something about that...I don't know if I ever really fully dealt with like the whole cancer and death thing at that age. I think I just like shoved it aside and moved forward...I never even went to a counselor about it and I probably should, but it's just something I never did. And I don't think I even fully comprehend the impacts and how it's changed me moving forward.

Magnitude of Impact

Each of the participants commented on the impact of having a sibling diagnosed with childhood cancer. The magnitude of this impact that each participant perceives falls along a continuum of influence. At one end of the spectrum, participants reflected that several years, even decades, have passed since their siblings were diagnosed, and this experience has less influence as time progresses.

So it's been 17 years since [my brother] had to deal with the cancer part of it...It was like it happened, and we moved on with life. It wasn't like an ongoing thing. So yeah it didn't affect me as much as when it first happened.

Participants at the other end of the spectrum express that this has been a defining experience for them, when asked about cancer's influence on their current lives. For these participants, having a sibling diagnosed with cancer, and the events following diagnosis, informed their career paths, daily interactions, and outlooks on life.

I didn't know a life without cancer in it until after she passed and...I would say it defines who I am today...it gave me a deeper appreciation for things in life...the type of person she was and who I project she would be now influences who I strive to be...it makes me stop to think about what I do every day, what I say every day, how I interact with people and my passions in life.

Additionally, some participants were ambivalent and are still processing the impact of their experiences with cancer and their family.

It's really hard to ascertain how much it is part of my identity or not. Because it's hard for me to say that I'm defined by this. But I often find that I kind of am...it's hard for me to be like I am defined by this one thing, or I am defined by the death of my brother because I feel like there's more and it shouldn't be that much of a defining moment but I think it kind of is.

Current Personality Snapshot

As siblings reflected on their past experiences of having a sibling with cancer and their processing of related events, siblings gave descriptions of their current identities, selves, and values. The participants summarized their current situations and internal processes, characterizing five subthemes which include their ability to focus on what is important, their passions and career interests, a tendency to remain reserved from others, an increased sense of empathy, and an awareness of their own mortality.

Focus on what is important

When asked to discuss the ways in which cancer has affected them today, 6 participants reflected on their ability to focus on what is important when circumstances become stressful. They are able to filter out less significant details which allows them to be less reactive and to be more easy going. Two participants also commented on their lack of interest in material things, which they related to their focus on more meaningful experiences in their lives.

I think I handle stress pretty good. I don't get worked up about small things, which I appreciate about myself. I'm in a stressful career so that's provided help to me knowing that I've been through enough as it is, there's not much that's going to get under my skin or rattle me. There's been positives, too.

I feel like I'm more open minded to, like, the way that things happen in life. Things will come up, and you could overreact, and then you have to take a step back, and then you're like, OK, it happened and how do we either adapt to it or resolve or just like kind of move on...Like I don't get as annoyed and upset as easily if things don't go my way because it's like well it happens and we kind of roll with it.

I have a fairly minimalist lifestyle, I don't really like to buy things much unless it has great utility to me but it's because I want to be able to -it's just not worth it; it's just not important. It's just a waste. So to me, I think I just really want to take advantage of my time, and I think that could definitely be influenced by his death.

Passions/careers

Eight of the 10 participants described how having a sibling with cancer, or the death of their sibling, has informed their passions and career paths. Some siblings followed in their siblings' examples of careers and hobbies. Some siblings took lessons they learned from their experiences in a family faced with childhood cancer, and pursued career paths in social work, policy, child life, and cancer research.

So I would always ask the doctors why can't you just take the blood out and put new blood in and just cure her? And it wasn't that simple, obviously. So I pursued the scientific research path. I finished all of my middle school, high school stuff, went to college and got a degree in molecular biology, got a master's degree in biochemistry. And I'm on the path towards working in cancer research. Because I want to figure out why...ever since I could talk, is what my dad says, I've been wanting to go into some sort of cancer based field whether that was medicine or research or whatever. I didn't really know. I've kind of narrowed that to the research side of it. I spent too much time around doctors and around pain to really want to do that to someone else. So going down the research path will help me find the answers but not necessarily have to administer them.

I was influenced to declare my major in [Human Development and Family Studies] because I said I don't know what I want to do but I know that I want to work with kids and I want to impact them in a positive way ... I specifically want to help kids who don't necessarily have a sibling with cancer but are impacted greatly by either chronic illness or anything in the family. It doesn't just impact patient but impacts siblings too...So being there for them and just giving them a little bit of light would be the best way to live my life and enjoy it.

Reserved from others

While most participants discussed their desire to work with people or that they felt more empathetic following their experience with cancer, 4 participants also discussed their hesitation to engage in deep connections with others. One participant reflected on the timeline of the cancer journey and how it coincided with a decrease in social relationships outside of the family. Another participant commented that while they maintain deep connections that were previously established prior to a cancer diagnosis, they were cautious in beginning new relationships. All 4 participants mentioned concern that others would not understand their experience or their families' experiences with cancer.

I think the part that I'm still struggling with the most tends to come in the area of either commitment or kind of establishing deeper than skin deep relationships with people. I didn't have like a serious girlfriend at all until 2 years ago from the time he passed. Really no interest, which I thought was the odd part was that it wasn't

like a struggle to do, or to meet people. I would get to know someone very superficially and rather than get more involved, I'm hesitant to open up to people and I find that that's probably related. Because I didn't have that issue before.

Empathy and helping others

Eight out of the 10 participants reflected on how they felt more empathetic towards others' struggles and experiences following their cancer journey. Several participants commented on their desire to give back and help others who either are in similar situations with cancer and loss or in various other situations which caused others distress. Participants expressed pride and positive regard for their tendency to step up for others.

I think it's allowed me to be more empathetic with people for sure. And having seen people go through cancer, like not even my brother, but kids that I've worked with at Camp Okizu, like seeing a kid fighting a life threatening illness is just one of the most baffling things you could think of. It seems so evil but it didn't come from a human it's just kind of like this unknowable thing. A kid that's fighting an illness that could die, it's just so baffling that it kind of has over the years allowed me to kind of see problems in the world but also be interested in those problems. And I really like to help people and be there for people, be kind to other people.

I am not an incredibly empathetic person but I think it has led me to- it has given me a larger ability to empathize with people going through personal problems similar to that. I think because not everybody knows what it's like to go through, I think it does give me a little bit of leverage in those situations where if I'm talking to someone else and they're talking about going through a cancer situation and I'm kind of able to relate a little bit and connect. And I think that can be a positive thing. I think that usually is a positive thing. So I think it's allowed me to be able to empathize better.

Awareness of mortality

When asked about the impacts of cancer, 4 participants discussed their increased awareness of mortality. Even at young ages, participants remembered discussing or learning in depth about

death and losing their sibling to cancer. For several participants, this increased sense of limited time led to a desire to live more in the moment and to seek opportunities that were fulfilling.

I think it had a huge impact. Coming from camp specifically, and I think the cancer part itself, I think the realization that anything- you always say that when you hear people dying are people getting really sick that anything can happen at any point in time so kind of like living for the moment. It definitely gave me that aspect and just like telling people how much you love them and appreciate them whenever you have a chance, especially family. Taking advantage of what you have, or not taking a vantage of what you have, but appreciating it.

I think it's definitely made me be someone who takes advantage of trying to get as much out of my life experience as possible. I'm going to die at some point in life and I want to have fun and I want to enjoy myself and that's going to be my priority... at the end of the day to me, personally, it's just I'm not going to waste my time and I'm not going to do a bunch of stuff I don't want to do and a bunch of stuff I don't feel like I should be doing and I'm definitely not going to pursue a career or a job that is just not well aligned with what brings me joy. So I think it's made me really take a look at what do I really want to do and where do I want to be and then let's figure out how I can make money doing it later.

Discussion

There is limited literature regarding the experiences of siblings of children with cancer, and even fewer studies involving the use of qualitative interviews with the siblings themselves. Additionally, many studies focus on siblings up to 2 years after diagnosis. This study involves the use of interviews to explore young adults' processing and perspectives of the influence of having a sibling with cancer in childhood on their current identities.

Participants described a range of experience and influence. They described their processing of their journey with cancer which included the magnitude of impact, the significance of their experiences through the death of their sibling for those who were bereaved, and reflected on new perspectives that they have gained through development. This study includes the experiences and narratives of young adults whose siblings are still alive as well as those who died from cancer. More commonly, studies include only those who are bereaved or those who have siblings who are cancer survivors. The results from this study show that the magnitude of impact of childhood cancer is not determined by bereavement. Siblings who are bereaved were not different from nonbereaved siblings in terms of magnitude of impact. There were siblings in both bereaved and nonbereaved groups who felt that they have been defined by their cancer journey, as well as siblings who described less of an impact on their current identity and time points. The researcher looked for additional patterns in the data across themes and demographics, but no patterns were found.

From a clinical perspective, it is important to not make assumptions about the impact of life experiences, such as having a sibling with cancer or having a sibling who died of cancer. Attributing too much or too little significance to this type of experience can alter the course of therapy or refocus the intention of therapy to a topic that is not substantial to a client or, on the

other hand, does not give enough significance to the experience of having a sibling who is diagnosed with childhood cancer or losing a sibling to cancer.

Additionally, nearly all participants described how important it was to have a space to make meaning. For some participants this space was a camp for siblings, and for others it was individual psychotherapy. Some participants expressed a desire to pursue a space for processing and meaning making in the future. When an event such as having a sibling diagnosed with cancer, in addition to the potential treatment and possible death, it is important for siblings to be able to process these experiences. For those who work clinically with families affected by childhood cancer, it is imperative that siblings are included in the families' psychosocial care and are given their own individualized space for processing of their cancer journey.

There were several identity concepts that arose out of the interviews as the participants depicted their experiences and impacts of cancer. Several participants commented on their increased awareness of mortality as well as their increased ability to focus on what is important. When a child is diagnosed with cancer, the siblings must negotiate and navigate through changes while keeping a fragile balance between realizing the severity of cancer, managing often significant life routines and family changes, and their own internal environments (Long, Marsland, & Wright, 2014). This ongoing process of adapting to so many unanticipated challenges during times of diagnosis, treatment, and sometimes death, appears to either continue or at least contribute to the outlook of many participants in this study.

Some siblings also noted their tendency to reserve themselves from others and to be hesitant to engage in deep connections. As described by Goldblatt (2011), children who experience bereavement, especially in adolescence, are isolated from their peers and are less likely to explore new components of their identities. While not all participants were bereaved,

the unique experience of having a sibling with cancer or having a sibling who dies from cancer is unlikely to be understood by peers, and consequently isolating from social situations and experience. Additionally, participants emphasized the importance of social support from both peers and other siblings, and those who felt more reserved commented on a lack of social support and reflected on the desire to make deeper connections. Barrera, Fleming, and Khan (2004), which found correlations between social support and lower symptoms of depression, anxiety, and fewer externalizing behavior. While this study did not assess mental health statuses or include mental health measures, participants expressed the benefits of having support and the long-term outcomes of having less social support such as feeling isolated and feelings of sadness.

Furthermore, Gass, Jenkins, and Dunn (2006) highlighted the importance of sibling relationships and support during stressful life events, and that they even served as protective factors for coping. This finding is particularly evident in this study as many participants commented on their relationship with other healthy siblings. Those with closer relationships to other healthy siblings or other siblings who are also bereaved expressed narratives that were more redemptive, which start negatively but end more positively, as opposed to siblings who had either strained relationships with other siblings or whose only sibling died from cancer (McAdams, Reynolds, Lewis, Patten, & Bowman, 2001).

Most siblings emphasized that they felt more empathetic and more understanding and openness to others and their experiences due to their families' journey with cancer, and bereavement. This increase in empathy aligns with previous research which describes experiences of posttraumatic growth in siblings of those with childhood cancer (D'Urso, Mastroyannopoulou, & Kirby, 2017). Similar to a study which specifically focused on bereaved siblings (Martinson & Campos, 1991), the participants from this study described their cancer

experience as having an influence on their personal growth. The changes depicted by both studies include positive outcomes such as building stronger relationships with other family members and learning about their own personal means of enjoyment, and negative changes such as withdrawing from social relationships and being hesitant to share their experience with other, even discussing the number of siblings they have (Martinson & Campos, 1991).

Often, literature describes siblings' experiences during or shortly after treatment (Houtzager, Grootenhuis, Caron, & Last, 2003; Houtzager, Grootenhuis, Hoekstra-Weebers, Caron, & Last, 2003) and rarely up to 5 years after treatment (Buchbinder et al., 2010). This study, however, gives insight into the lived experiences of young adults whose siblings were diagnosed with childhood cancer several years, even decades, and well into adulthood.

Strengths and Limitations

Participants were recruited through snowball sampling which allowed for quick recruitment through specific communities. However, this also can lead to the lack of diversity and variation in participant demographics across the sample, which affects the applicability of these findings to a large sibling population. Some of the participants are known to the researcher, which can introduce bias, yet the researcher's knowledge of this population's experiences allow her to be able to ask more applicable and appropriate interview questions for siblings. The small number of participants is limiting, but this study can serve as a pilot for a larger study with siblings of children with cancer.

Implications for Social Work Practice

This study identifies three qualities and goals for social work practice when working with siblings of children with cancer. The spectrum of influence of cancer on siblings' long-term development and identity shows that the degree to which these impact a sibling differ; it is

important to not assume that childhood cancer experiences define a sibling's life, yet can carry life-long influence. Like Gerhardt, Lehmann, Long, and Alderfer (2015) assert, siblings of children with cancer are psychosocially at-risk and a psychosocial standard of care for this unique group with evaluations and intervention protocols is needed. Additional supports and intervention targets include facilitation of family communication, increase of sibling social involvement, and increased sibling participation in care and knowledge of diagnosis and treatment (Long, Lehmann, Gerhardt, Carpenter, Marsland, & Alderfer, 2018). Siblings also explicitly described the need for space to make meaning, which social workers can provide through therapy, camps, and support groups.

Future Research

Future research opportunities could include a study with a larger group of siblings to explore correlations between effects on identity and bereavement, birth order, and gender. None of the participants in this study had children, but it would be interesting to gain insight into how having a sibling with cancer or having a sibling die from cancer could later influence parenting styles or identity as young adults become parents. Additionally, intervention and evidence-based studies are limited, so research exploring the impact of camp or therapy or other interventions specifically on identity could be beneficial for the community at large and providers who work with siblings of those with childhood cancer, not only as children but throughout their lives.

Conclusion

The purpose of this study is to provide insight into the experiences of young adults and their identities several years, even decades, following their siblings' cancer diagnoses, and sometimes deaths. The semi-structured interviews were conducted with 10 participants who had a sibling who was diagnosed with cancer in childhood. The narratives from the participants in this study provide a wide array of cancer experiences and family struggles during and after treatment. The data from the interviews also show several overlapping themes that the participants shared. Participants differed in their ages at diagnosis, their place in the birth order, whether their sibling was still alive or not, how much cancer and/or their sibling's death has affected the person they are today, and the ways in which they choose to involve their sibling in their lives now. Participants shared common themes around being more aware of their mortality, a desire to help others and pursue helping careers, their increased empathy towards others, their more refined ability to focus on what is important to them, and recognition of the significance of finding a space to make meaning around an experience like childhood cancer. The implications of this research inform providers that childhood cancer can, but does not always, define siblings' lives or identities. Additionally, the loss of a sibling to cancer in childhood does not necessarily determine magnitude of impact that that experience has in the long term. It is also important to note that changes and challenges that occur or are used to cope through treatment and bereavement can persist well into adulthood, like remaining reserved or closed off to others and potential social supports. Even with the stressors and family change that accompany a sibling's cancer diagnosis, many siblings perceive positive changes like increased empathy and search for greater purpose in their professional endeavors. The common experiences that siblings endure when a child is diagnosed with cancer such as less parental attention, worry for their sibling, and

its enduring effects into adulthood deserve more overarching acknowledgment and validation. From a clinical perspective, there must be more providers who understand the range of sibling experience in order to make space for and facilitate meaning making of childhood cancer and bereavement experiences for siblings.

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Tables

Table 1. Participant Demographics.

			# of		Which	Participant	Age of child	
Age	Gender	Siblings	Birth order	diagnosed	sibling	age at	who was	Bereaved
						diagnosis	diagnosed	
1	27	woman	1	1/2	2/2	7	4	no
2	23	man	4	4/4	1/4	9	16	yes
3	23	woman	2	3/3	2/3	not born yet	2	yes
4	21	woman	2	1/3	2/3	13	10	no
5	21	woman	0	1/2	2/2	4	baby	yes
6	25	woman	3	3/4	1/4	11	16	yes
7	20	woman	2	2/3	1/3	8	11	no
8	28	man	3	2/4	1/4	15	17	yes
9	24	man	3	2/4	3/4	3	10 months	yes
10	21	woman	3	2/4	4/4	12	5	no

Table 2. Themes expressed by participants.

Theme	Subtheme	# of participants
Processing	Perspective that comes with development	7
	Magnitude of impact	10
	Different experience due to loss	6
	Space to make meaning	9
Current identity snapshot	Focus on what is important	6
	Passions and Professional Endeavors	8
	Reserved from others	4
	Empathy and helping others	8
	Awareness of mortality	4

Appendix A

Recruiting Siblings whose Brothers or Sisters were
Diagnosed with Childhood Cancer

Looking for Young Adults Ages 18+

For a One Time Interview

Study Purpose: To gain insight into the influences of childhood cancer on siblings in adulthood.

Criteria: 18 years or older AND have a sibling who was diagnosed with cancer before the age of 18

Commitment: 1 online interview which will last about one hour

Please contact Brittany Lawton to see if you qualify and participate:

blawton@gm.sl.c.edu

Appendix B

SARAH · LAWRENCE · COLLEGE

Childhood Cancer and its Effects on Sibling Identity in Adulthood: Consent Form

Brittany Lawton, blawton@gm.slc.edu

I am asking you to take part in a research study at Sarah Lawrence College. Please read through the following questions and responses and **ask any other questions** that will help you to decide whether or not to participate.

What is the purpose of this study?

- The purpose of this study is to learn about the impact of childhood cancer on siblings' identities in adulthood through interviews.

Why am I being asked to participate?

- You are being asked to participate if you are over 18 and had a sibling who was diagnosed with childhood cancer before you and your sibling reached 18 years of age.

What will I be asked to do?

- If you would like to participate in this study, you will join the researcher in an online video interview. You will be asked 10 interview questions regarding you and your sibling's experience with cancer.
- For this study, there will be one interview session that will last about one hour.

Is my participation voluntary?

- Participation in this study is completely voluntary. You may choose to opt out of the study at any point; this will not your relationship with the researcher or Sarah Lawrence College.
- You also can choose not to answer specific questions without having to justify your choice.

Are there any benefits or risks associated with my participation in this study?

- This study has minimal risks. First, there may be some discomfort when discussing negative impacts of your siblings' cancer diagnosis. Second, you may become emotional when discussing your experiences you have encountered due to a cancer diagnosis. I will provide a list of counseling resources following our interview should you want to seek additional support.

Will I be compensated for my participation?

- Participants will not be compensated.

Will the information I provide be kept confidential?

- You will not be identified in any written or oral report of the research study.
- The researcher and her graduate thesis advisor are the only people who will have access to your data, and it will be stored securely.

If I have any questions or concerns after the study how can I contact you?

- You may contact the researcher, Brittany Lawton at blawton@gm.slc.edu or 530-401-4317.

- You may also contact the researcher's faculty advisor, Barbara Schechter at schechter@sarahlawrence.edu.

Who can I contact if I have questions about my rights as a research participant?

- The IRB co-chairs Professors Elizabeth Johnston (914 323 6672) and Claire Davis (914 395 2605) at irb@sarahlawrence.edu

Please indicate with your signature on the space below that you understand your rights and voluntarily agree to participate in the study and to have the interview recorded.

Signature of Participant

Date

Print Participant Name

Brittany Lawton, Investigator

Date

Appendix C

Demographic Questions

1. How old are you?
2. What gender do you identify as?
3. With which race or races do you identify: White, Black or African American, American Indian or Alaska Native, Asian, Native Hawaiian or Other Pacific Islander, or other? You can choose more than one.
4. Do you identify as Hispanic or Latino?
5. How would you describe your religious and/or spiritual identity?
6. How many siblings do you have?
7. Where are you in the birth order?
8. Which sibling was diagnosed with cancer, and what ages were you and your sibling at that time?

Appendix D

Semi-Structured Interview Questions

1. Can you tell me about yourself? (Follow-up if no response or for further expansion: This can include hobbies, interests, friends, activities, school/work, groups you're involved with.)
2. Please share about your family. What are the relationships like between individual family members? Do you have a favorite memory with your family like a vacation or a special event?
3. Is your sibling still alive?
 - a. If yes
 - i. What is your relationship with your sibling who was diagnosed with cancer like?
 - b. If no
 - i. How long ago did they die, and was their death related to their cancer?
Could you describe the impact of this loss on your life?
4. If have other siblings: What is your relationship like with your siblings who were not diagnosed with cancer?
5. Tell me about your experience with cancer starting with when you heard about your sibling's diagnosis? (Follow-up: How did you feel about the diagnosis? Treatment? Where did you stay? What was your relationship with your parents like during this time?)
6. What impact, if any, do you think cancer had on the person you are today?
7. If you were to describe yourself in five words, what would they be?
8. What kind of professional work are you pursuing or do you hope to pursue?

9. Is there anything else you would like to add that has not been asked?