

# Understanding the lived experience of Latino adolescent and young adult survivors of childhood cancer

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## Abstract

**Purpose** The purpose of this study was to investigate the experience of surviving cancer for Latino adolescents and young adult (AYA) survivors of pediatric cancer.

**Methods** Using a phenomenological approach, this study focused on the experience of cancer survivorship through in-depth interviews with 14 Latino AYA survivors (16–29 years) diagnosed as young children (0–15 years) and at least 1 year post-treatment

**Results** Four essential themes about the Latino AYA experience as childhood cancer survivors emerged from analysis: borrowed strength of family and hospital staff; sustained positive attitude; perceived vulnerability; branded a cancer survivor. According to these participants, the lived experience of surviving cancer was predominately positive. These emerging adults were able to focus on the positive lessons learned from their cancer experience such as the importance of personal relationships and an optimistic outlook on life. Yet, it was clear that long after these survivors had been labeled “cured” by the medical team, cancer continued to be a large part of their existence.

**Conclusions** The results indicate that these emerging adults faced their cancer experience with optimism, leaned on relationships with family and health care professionals, and demonstrated resilience through their cancer treatment and beyond.

**Implications for Cancer Survivors** This unique description of Latino survivors' experiences demonstrates that they simultaneously face uncertainty and identify positive influences of

the cancer experience in particular unwavering familial support. These findings provide opportunities for health care providers to better understand this rapidly growing population and to create culturally resonant programs that can promote their long-term health and well being.

**Keywords** Survivorship · Hispanic/Latino · Psychosocial · Quality of life

## Abbreviations

NCI	The National Cancer Institute
PTSD	Post-traumatic stress disorder
AYA	Adolescent and young adult
UTHSCSA	University of Texas Health Science Center San Antonio
PI	Principal investigator
SES	Socioeconomic status
QOL	Quality of life
HRQOL	Health-related quality of life

Due to enhanced cancer therapy most children diagnosed with cancer in the last two decades survive into adulthood [1]. Since 1993, The National Cancer Institute (NCI) has studied survivors of childhood cancer and provided scientific knowledge about the physical and cognitive late effects of childhood cancer. Survivors diagnosed as children are more likely to experience chronic health conditions compared to their peers [2]. These conditions may include infertility, physical impairments, and evident cognitive disabilities [3–5]. Cancer continues to affect the lives of survivors well beyond treatment, yet the psychosocial implications are not well understood. The existing literature on young adult survivors of childhood cancer shows varied psychosocial outcomes. Several studies [6–9] found that pediatric cancer survivors were more likely

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than peers to have symptoms of anxiety and post-traumatic stress disorder (PTSD) as they grew into young adults. The NCI report states that survivors may have difficulty transitioning from pediatric to adult health care practitioners, have higher levels of depression/anxiety, attention deficit, and infertility issues, as well as increased risk for other adverse behavioral, social, and physical outcomes [10]. Another study showed that survivors were likely to have lower self esteem compared to their healthy peers [11]. Finnegan and colleagues [12] found that over 50 % of their sample reported one or more adverse symptoms including: lack of energy, worry, pain, difficulty sleeping, irritability, and feeling sad. Moreover, the combination of symptoms such as fatigue and feeling sad impacted survivors quality of life (QOL) scores more than any one symptom alone [12]. Two systematic reviews examining the quality of life in survivors of childhood cancer found mixed results with contradictory findings across all studies [13, 14]. In addition, due to broad variations in study designs, measurement tools, and conceptualizations it was difficult to compare studies and draw conclusions [13, 14]. Nevertheless, they were able to extrapolate overall trends from the findings including the fact that most survivors worry about their future offspring struggle with employment and health insurance [14], yet report good psychosocial functioning even when faced with poor physical well being [13]. Reports from the Childhood Cancer Survivor Study also found that overall survivors were psychologically healthy and had good quality and life satisfaction [15, 16]. In particular, Zebrack and Landier's [17] findings suggest that the survivor's *perception* of how cancer has impacted their life is a significant predictor of distress and QOL. These varied findings of positive and negative psychosocial outcomes for childhood cancer survivors make it evident that there is still much unknown about the complex variables that affect their well being.

The current literature on survivors of childhood cancer seldom includes outcomes for ethnically diverse and low socioeconomic populations [18]. Particularly understudied are the experiences of Latino cancer survivors and the meaning of a cancer diagnosis to this population [19]. Childhood cancer accounts for 2.3 % of total Hispanic/Latino cancer cases in the USA as compared to .7 % of childhood cancer in the total population. The MD Anderson Cancer Center estimates in the next two decades that cancer cases in the Hispanic/Latino population will increase by 142 % compared to only 42 % in the overall U.S. population [20]. These rates, along with the fact that Latinos are the fastest-growing ethnic group in the USA make research in this area critical [1]. Studies of adult cancer survivors including ethnically diverse samples are steadily increasing but few are focused on Latinos [21], and of these most examine Latina breast cancer survivors [21–23]. These studies suggest that adult Latino cancer survivors report greater pain, financial difficulties, fear of recurrence, fear of death, and in some cases lower life satisfaction

compared to whites [24–26]. Although Latino children have the highest rates of some childhood cancers such as leukemia there are only a handful of published studies that examine the young adult survivors of these cancers [27–31]. The limited studies that examine health-related quality of life (HRQOL) and include cultural and ethnic minority young adult survivors of childhood cancer suggest that ethnic status may be associated with poorer psychosocial outcomes, and higher rates of emotional distress compared to their white counterparts [32, 33]. One study found that adjusted for socioeconomic status (SES) adverse outcomes for survivors of childhood cancer were not affected by ethnic minority status, yet they also found that ethnic minority survivors were more likely than their peers to have lower SES [30]. Casillas et al. [27] used a mixed method design to uncover issues in measuring HRQOL in this population. For example, although survivors routinely reported their physical health and HRQOL as “good” on surveys when the survivors were interviewed they were able to qualify their reports noting chronic pain, infertility, and frequency of illness that made them feel different than their peers [27]. Casillas and colleagues findings also indicated that family relationships were key to the HRQOL of Latino survivors [27, 31]. Thus, cultural backgrounds may affect the cancer experience of Latino adolescents and young adult survivors of childhood cancers. The literature shows several shared cultural values among Latinos that may influence their cancer experience [22, 23, 25, 34]. These include “*collectivism*, the importance of friends and extended family in helping to solve problems; *simpatia*, the need for smooth interpersonal relationships; *respeto* the need to maintain one's personal integrity;... *fatalism*, cancer is a matter of fate or punishment from God; and *familism*, the significance of family over the individual” [34]. In particular, the effects of familism have been well documented in the literature. Familism is defined as a social pattern in which family interests take precedence over the individuals. Sabogal et al. [35] found that familism was specified as a core attribute for most Hispanics and Latinos when describing their culture. The high level of perceived family support seems to be the most essential dimension of Hispanic/Latino familism. This idea of familism was supported in a recent study [28] which explored how Latino adolescent and young adults (AYA's) who lived through cancer found a way to cultivate meaning from their experience. Findings revealed that family relationships, community, and faith were paramount for this group of AYA survivors. This is similar to findings from the adult survivor literature [22, 23, 26]. The literature indicates that more research is needed in order to assess the impact of culture and ethnicity on the long-term health and wellness needs of Latino cancer survivors. This study aims to build on previous studies of Latino cancer survivors by exploring the impact of a childhood cancer diagnosis on current Latino AYA's. This study explores more fully the initial findings of Jones et al. [28] by studying

Latinos in a different setting and expanding the population to include a wider age range at diagnosis.

The purpose of this project was to conduct a qualitative study with Latino adolescent and young adult survivors of childhood cancer to discover the experiences and personal meaning of surviving cancer for this population. A hermeneutic phenomenological approach focused on the experiences of young adult Latino childhood cancer survivors was employed to gain understanding of the lived experience of Latino AYA's. This approach may provide opportunities for health care providers to better understand the rapidly growing population and better assist in creating programs that will promote their long-term health and well being.

**Methods**

The conceptual orientation of this project was based on a resiliency and health promotion framework. The experience of trauma, such as a life-threatening illness, often leads to a personal search for meaning and purpose [36]. Many studies have shown that receiving a cancer diagnosis precipitates a personal search for meaning/purpose in the patient/survivor [28, 37–39]. Finding a sense of meaning has been shown to be a source of resilience and positive adaptation after illness, loss, and trauma [36]. Meaning-based research will allow an exploration of the unique experience of Latino AYA survivors of childhood cancer and begin to explain how they can adjust positively to the cancer experience. This study hopes to bring a deeper understanding of this population's experience. The use of Phenomenology provides the richest and most descriptive data [40]. Therefore, it is the ideal research process for exploring the survivors' experiences. Knowing the common experiences of these survivors can be valuable for therapists, health personnel, and policymakers who are responsible for identifying best practices for survivors care [40].

**Setting**

The setting for data collection was The University of Texas Health Science Center San Antonio (UTHSCSA) Childhood Cancer Survivor Clinic and the American Cancer Society offices in San Antonio. Over 65 % of the patients served by the UTHSCSA clinic self-identify as Latino.

**Sample**

After the study was approved by University of Texas at Austin and UTHSCSA institutional review boards criterion sampling was used to identify participants who met the study's inclusion criteria. This study's participants met the following inclusion criteria: a cancer diagnosis between the ages of 0 and 15 years, at least 1 year post-treatment, self-identified as Latino, English

speaking, and currently an adolescent or young adult age 15–30. Exclusion criteria were patients who had relapsed as their experiences might be quite different from those who had not relapsed.

Eighteen participants were recruited and interviewed; 14 interviews were transcribed and analyzed. Three participants were excluded because they had experienced a relapse. One participant was excluded because their age was 10 years older than the second oldest participant. Therefore, their developmental life course was likely very different than the other 14 participants. Age of participants ranged from 16 to 29 years, and their years off treatment was 1 to 17 years. There were 11 females and 3 males, and all self-identified as Latino. In accordance with phenomenological methodology 10–15 participants was considered an adequate sample size to reach saturation [40]. Detailed demographic data on each participant can be found in Table 1.

**Procedures**

Fourteen in-person, in-depth interviews, lasting between 40 and 70 min, were conducted at one time point with each participant. The interviews were conducted by the first author using the attached interview guide (Appendix A). The first author is a child life specialist with extensive experience working with families in many medical settings including a pediatric oncology unit. The interview guide builds on a previous study conducted by the second author [28] and was developed to explore the key concepts of the cancer experience based on previous research on meaning making and childhood cancer, clinical experience, and feedback from the research team. The survivors were asked eight open-ended questions aimed at eliciting a rich description about their

**Table 1** Participant demographic data

Participant	Current age	Age at diagnosis	Diagnosis
1	16	14	Pineal gland tumor
2	20	12	All
3	29	14	Ewing sarcoma
4	19	18 months	Retinoblastoma
5	18	8	Leukemia
6	18	6 weeks	AML
7	21	12	Ovarian
8	16	6	Hodgkin's lymphoma
9	19	15	Hodgkin's lymphoma
10	20	2	Leukemia
11	18	3	ALL
12	18	14	Brain tumor
13	22	5	AML
14	29	15	ALL

cancer experience and their current lives. This approach allowed the researchers to gain a deep understanding of the experiences of the survivors. The purpose of each interview was to allow a full description of the experience from the participant's point of view.

### Data analysis

The researchers used a combination of analytic approaches to phenomenological analysis as described by Moustakas [41]. Prior to conducting interviews the first author recorded a list of assumptions about the population being studied in an effort to address the research with “a fresh perspective toward the phenomenon under examination” [40]. The interviews were first entered into Atlas.ti 6 software. Organization of data began when the research team conducted a naïve reading and studied the entirety of the data including all transcribed interviews. The data was reduced by listing all significant statements and eliminating those that were repetitive, vague, or overlapping. This process allows the researchers to obtain the meaning units that were then categorized into themes [41]. This data contained 14 interviews of which the first 5 interviews were coded and analyzed at an earlier point. The initial themes were validated by checking them against the nine subsequent interviews and the complete

transcriptions, making sure they were either explicitly expressed or compatible. The reliability of the themes were assessed through peer checking using a panel of experts on Latino adolescent and young adult survivors of childhood cancer [42, 43]. This group of experts included an oncologist, nurse, and social worker from the survivorship clinic at UTHSCSA. The experts supported the fittingness of the final themes used to describe the experience of these survivors. In hermeneutic phenomenology, validity refers to the fact that there are no internal contradictions within the study [44]. Arranging these meaning units into clusters resulted in the four basic themes. Table 2 contains examples of theme clusters that emerged from their meaning units. These validated themes were labeled as the core of the experience and were used to develop textural descriptions or “what” the participants experienced. Next, the structural descriptions or “how” the experience happened was formed by reflecting on the setting and context in which the phenomena was experienced [40]. Finally, from the integration of the textural and structural descriptions into the meanings and themes of the experience the essence of the phenomena was constructed. This final synthesizing of the data and creation of a composite description of the lived experience for the group as a whole was the ultimate goal of this phenomenological study.

**Table 2** Example of theme clusters and their associated meaning units

Borrowed strength of family and hospital staff	Branded a cancer survivor	Positive attitude is key to surviving	Perceived vulnerability
The nurses are what I loved about the hospital.	Being a survivor makes you relate so much to others going through cancer.	You just have to accept it and move forward.	Cancer left me feeling vulnerable to illness even though I am healthy now.
I felt like I could talk to anyone at the hospital.	Cancer changed everything for me. I don't know where I would be without my cancer experience.	Staying positive is key. Humor helped me survive.	Fear of relapse is ongoing.
The hospital staff helped me through the cancer experience.	Cancer inspired me to become a doctor.	Try to instill hope in younger children. I look at things in a positive way even death, it is natural, no reason to fear it.	Fear of relapse and desire to be reassured more often by medical staff that the cancer is still gone.
The nurses still remember me. I still visit the hospital. It is like my second home.	Friends treat me different when they find out I had cancer. It is a big deal to have survived cancer; it made me who I am.	Kids still had fun in the hospital, laughed and played.	I don't feel healthy right now.
The medical staff really cares for me.	I just want to feel normal. I want to be treated like everyone else.	I may have lost my eye but others suffered much worse, I'm lucky.	I don't want secondary cancer to happen to me.
My parents were always there for me.	I always remind myself I had cancer so I can just keep going through hard times.	Stay positive and be healthy to get through cancer.	Everything seems fine but there are scares I go through.
I survived cancer with all the love and care from my family.	I can just keep going through hard times.	Cancer gave me confidence.	Feel that cancer will come back in survivors as they get older.
My grandparents really helped take care of me.	It is nice to know other people who went through all the same mental and physical pain.	I'm very optimistic and I never lose that.	I can get sick a lot easier and more often now.
My mom is always there for me. I was never by myself.	We are still standing, we are still surviving.		I have to take more precautions (to stay healthy) than my peers.
			Fear of secondary cancer.



## Results

Four essential themes about Latino AYA survivors of childhood cancer experiences emerged from the analysis: *borrowed strength of family and hospital staff; sustained positive attitude; perceived vulnerability; branded a cancer survivor*. These will be discussed below.

### Borrowed strength of family and hospital staff

Many participants expressed that they would not have been able to survive their cancer experience without support from their family and hospital staff. Responding quickly and spontaneously to how they would describe their experience of surviving cancer participants made statements like: “Support, tremendous support”; “With my family, my family was always there”; “My nurse was the one who helped me with it the most”. This idea of borrowed strength or using the ongoing support of others to survive was apparent in the following statements:

With the support of my family and friends and loved ones, my doctors, my nurses were all great, very supportive and so that contributed to me overcoming that (cancer). (19 year old survivor)

I mean it does feel good that I've done that (survived cancer) but you know it wasn't even necessarily myself who did it. It was everybody else who helped me. (18 year old survivor)

It was clear that family played a big role in these survivors' lives. They attributed their ability to cope to the strength they gained from family support, as reflected in these statements:

My mom would come home and...she would always talk to me, like everyday. Just for a good while and just like you know, tell me, “You can get through this.” She's like, “You're strong.” She's like, “We're gonna take care of you, we're gonna help you.” She's like, “everybody at the hospital cares and they're gonna help you.” She was just always, like everyday, just helped me through it. (20 year old survivor)

We went through a lot. I mean my whole family was always there. They were very, very supportive. I mean there was probably counted days, if not hours, that I was by myself...throughout the whole day I had somebody (mother, grandparents) there. All the time. (29 year old survivor)

This survivor described her family as her motivators while she was on treatment:

I think they (family) helped through the whole thing, because they were always my motivators. You know, knowing that they were always there, knowing that I always had their, you know, 100 plus percent support,

you know, that made a very, very big difference in my way of seeing how my treatment was going, they played a huge, huge part in my treatment and the outcome of it. (29 year old survivor)

Participants also expressed closeness to health care staff and implied that this made the experience of going through treatment bearable, as exemplified by the following quote:

That's one thing that makes the hospital seem like a family. Like a second home to me, because we always talked to everybody. We didn't make it seem like we were here because you have cancer and you need to go through this stuff. It was just like we're going here because you have to go through this but let's have fun. (22 year old survivor)

These bonds with the medical team and their families continue to be powerful influences in these AYA's lives. They continue to express their close relationships with their family and remain connected to the hospital staff through ongoing visits and special events. It seems that many of these young adults feel they borrowed the strength of others during their cancer experience and this contributed to their survivorship.

### Sustained positive attitude

Many of the young adults suggested that having a positive attitude is paramount to enduring the cancer experience. While recognizing that cancer treatment was extremely difficult and frightening, some survivors found it helpful to avoid negative thoughts:

Stay positive and have an open mind but always believe that everything is going to be fine. Because I think that negative thoughts are an addition to the cancer and everything and it's just all the negative thoughts and everything will bring you down worse. You'll just feel much more horrible and you'll be thinking that, that things are gonna take a turn for the worst. Keeping positive is one of the keys to staying... to surviving. (29 year old survivor)

Cancer made me stronger, like, the old saying what doesn't kill you makes you stronger. So, I defeated cancer. I conquered it. You could always beat it. Just stay on the positive side. Don't think negative. Every morning I wake up and I can wiggle my toes. Hey, I'm happy! (18 year old survivor)

When asked how they were able to survive their cancer many participants expressed a positive outlook as instrumental:

How I survived cancer?—just keeping a positive attitude, always had to stay strong..., obviously I was upset

but I couldn't like just constantly be upset because I'm not, not gonna beat it that way. So I had to stay strong. (18 year old survivor)

Some participants indicated that having cancer as a child rather than an adult helped them to maintain an optimistic perspective:

Because a lot of times if you get it when you're older, like, you know family stresses you out and I believe that if you're thinking badly and you're putting a negative energy on something that results in that way. And being a little kid I just it was like, "OK another day at the hospital" like I didn't even think much about it (cancer). Like I said, when you're older and you're worried about your life and your kids and your money and your jobs and everything. When I was a kid, I had nothing else to worry about except for, "What dessert are we having tonight?" (20 year old survivor)

For other participants this positive attitude has remained a part of their life and they see it as one of their strengths. "Now I think, like, my biggest strength is just I guess being positive". This 18 year old survivor reflects on her self confidence, "I'm very confident and...optimistic. I never lose that. I think I've always been that way; it's just that it grew stronger as I was diagnosed, 'Cause I needed it more.'" Another 16 year old survivor comments on her continued ability to persevere during difficult times:

I'm pretty good about no matter what the situation is, no matter how bad it is I just keep going. Even if you're down in the dumps as worst as you possibly can, I just keep moving cause that's all I can do. So, I'm pretty good about things like that. Just looking forward looking at the best of things.

This 29-year-old survivor explained that none of his current challenges in school compare to what he experienced as a child so that helps him remain motivated:

Quitting is not an option in my book. When I've done something like this (survived cancer) then I'm a survivor before so it just keeps me going and keeps me stronger. Okay well I've done this (cancer), so this (current problem) is not going to stop me.

These survivors clearly utilized strength and gained meaning from their life-threatening experiences and continue to use this to focus on the good in their lives.

#### Perceived vulnerability

While survivors overall tended to focus on the positive they did express worry and concern specifically in one area; their vulnerability to relapse. These Latino AYA survivors of

childhood cancer all shared some anxiety and a perceived vulnerability to illness that differs from their peers who often have a sense of invincibility [45]. All the participants, regardless of how many years past treatment, indicated anxiety about relapse and/or a concern that they were now more susceptible to illness:

Well, it's not necessarily when I was going through treatment, since I was so young, but like now that I'm a little older, it's just like scary to think that I could have died from it. Or that it can come back and that you pretty much have to like be conscious of all that for...forever. (19 year old survivor)

My biggest worry is (the cancer) coming back; that's what plagues everybody. If you're a survivor hoping that (cancer) doesn't come back or you're susceptible to a different type of cancer coming in depending on what kind of medicine you've got and how that impacted your body you have chances of coming out with maybe some kind of heart problems or kidney problems or some kind of secondary cancer, leukemia or something like that. (22 year old survivor)

This survivor who had been cancer-free for over a decade shared how he tried to live a healthy lifestyle:

I always think that it may come back some time. A concern for it not to come back and try to do everything I can possibly to be preventing it. Try to stay healthy and not do the things that will put me at risk anymore. (29 year old survivor)

Many of the participants expressed ongoing health concerns that were constant reminders that cancer had taken a toll on their body. Survivors described their health concerns, "You could develop things a lot easier or you can get sick a lot faster." "I don't necessarily know if it's from the cancer, but I probably have fifty things wrong with me." Another participant stated:

I think I am more vulnerable to more diseases now. I know physically I'm strong but it's like my body—like I don't know how to explain it—but with the cancer I feel like there is a wall there that we are born with; it was brought down. Because since my chemotherapy I think it just ate it away. So in other words I could get cancer again from second hand smoking and I'm thinking like I can get another form of cancer due to radiation. So I could get more things faster. (21 year old survivor)

This loss of invincibility is not always apparent on the surface of these survivors' lives. It is in sharp contrast to their often visible optimistic and upbeat personas. It is a powerful reminder that "cured" is not an easily integrated concept for cancer survivors.

### Branded a cancer survivor

Participants all indicated an understanding that cancer has had a substantial effect on them throughout their entire life. Cancer was not just an experience that happened in their past. They seemed to feel that cancer is a branded part of their identity that could not be shed. This survivor explained, “My biggest struggle in life has to be the cancer and the whole process of overcoming it and being able to say, ‘it’s not a part of me—it’s gone.’” This idea that the cancer experience is ongoing was reiterated by these survivors:

Luckily in my case I was able to catch it in time and so for me overcoming that (cancer) I’m glad to be alive and I’m glad that that part of my life is done with. But it is going to be with me forever. (22 year old survivor)  
I mean I’m very, very open about it (cancer experience), you know. It was a part of my life, you know, it’s something that I went through whether it was a bad experience or good experience...I learned a lot from it. My whole family gained a lot of knowledge from it. So, I talk about it free just like it’s happened yesterday or the day before...It (cancer) was something I know what I went through and it’s, I think it’s made me the person that I am now. (21 year old survivor)

Another survivor felt that it was important for survivors to continue to educate others and speak of their cancer but made it clear that he did not want it to be seen as a negative:

I think it’s important to help and we need to spread the word that there is survivorship and there is a lot of people out there who are in their 20s or in their teens surviving this, and, not putting it past them, but not holding it against themselves. (22 year old survivor)

Some survivors recognized the impact cancer had on their identity but embraced it as a beneficial aspect of the experience:

I think it changed everything. I really don’t know who I would be if I didn’t have cancer. I know people have regrets and things and they wish hadn’t happened but I really don’t ever wish...I mean it sounds kind of silly but I don’t wish things were different because then I don’t know at what stage I would be at. (18 year old survivor)

Some felt that people’s perceptions and expectations of cancer survivors affected their relationships:

I think it’s important for people to know, but I don’t want them to judge me about the bad and be like, “Oh I’m a cancer survivor,” and yea but they automatically have this feeling that, “Oh he’s a generally good person because he had cancer,” I mean, I want people to know me first, and then I’ll say, “Well, I overcome this stuff

and this is, I guess, what made me, this is what makes me who I am today.” (29 year old survivor)

I’m different and I want to tell somebody. But no, I don’t go around and offer that because I feel like I don’t want them to treat me different. Because I know some of my friends now, they still kind of treat me like I can’t really, like I can’t question you, or I can’t mess around with you because like oh you know, you’re different. (16 year old survivor)

This was reiterated by this survivor that shared how staff at an emergency clinic became friendly and accommodating only after they learned that she had survived cancer:

Just saying that simple word cancer. It could go different directions for people. When you say cancer they think whoa “Are you okay?” With cancer survivors they say “They had cancer but they survived it!” It’s another word now to describe you.

Survivors just felt different than peers, as revealed by this comment, “If I sit down and think about it I mean I really think, ‘Wow’ that actually I am really a lot different than normal people, but I guess I’m just really used to it.” Some of the participants seemed to struggle with being constantly identified as a survivor when they desired a sense of normalcy. A 19-year-old survivor expressed her frustration with friends treating her differently when they find out about the cancer, “It’s like you know, we’re fine. We’ve gotta have our checkups and we’ve gotta take our meds but I can run, I can talk, I can move!” One survivor offered this parting thought, “I’m just the same individual just with the black cloud of previous experience when I was in the younger years. Just don’t look at us differently.” Cancer remains part of these survivors’ daily lives and is incorporated into who they are and how they relate to the world. The cancer experience creates this sense of permanent identity change leading to the feeling that they have been branded forever as a cancer survivor which includes positive and negative connotations for these young adults.

### Discussion/implications for practice

The four themes, *borrowed strength of family and hospital staff; sustained positive attitude; perceived vulnerability; branded a cancer survivor* constitute the essential experience of survivorship for these Latino AYA’s. These findings underscore the significance of family and staff support, the desire to maintain a positive focus, the impact of cancer on identity and the sense of vulnerability of long-term health for Latino adolescent and young adult survivors of childhood cancer. These results are consistent with previous research about the ongoing consequences of cancer on survivors’ sense of identity causing cancer to be a “part of who they are” [29, 46]. This study also supported previous findings that for some Latino survivors a

certain amount of stigma associated with cancer persisted years after the diagnosis [31].

For many Latinos, a cancer diagnosis brings the uncertainty of fear of relapse and ongoing health problems [25–27, 29]. For these adolescents and young adults this created a premature loss of invincibility that is evident even years after the end of treatment. Adolescents are developing their sense of self as they are maturing into adulthood and being a childhood cancer survivor can alter that process. What must now be identified is exactly how this impacts their psychological and emotional development. Comprehensive oncology survivorship clinics that address the typical issues of AYA's such as risky behaviors, intimate relationships, and growth and development are being established. These programs include opportunities for face to face or online support groups, individual counseling, and provide an ongoing link to the survivor's medical team. They emphasize the promotion of health behaviors including nutrition awareness and increased activity in order to help childhood cancer survivors feel more in control of their overall health. The healthcare team can only begin to develop programs that meet Latino AYA childhood cancer survivor's long-term health and wellness needs if more studies identify the needs and concerns unique to this population.

Many past studies have focused on the deficits created by a cancer diagnosis [7, 47, 48]. This study offers a description of the survivors' experiences and demonstrates that they simultaneously face uncertainty and fear, and identify positive influences of the cancer survival experience. Furthermore, these findings indicate that Latino childhood cancer survivors form cognitive meaning out of their experience that shapes their growing identity. The theme of sustained positive attitude is closely aligned with other studies findings of psychological growth and positive change gained from the experience of a life-threatening illness [49–51]. These outcomes have been discussed in the literature as post-traumatic growth and occur when survivors are able to thrive despite the challenges they faced during their cancer experience [52]. This is often achieved through the ability to make meaning out of their experience consequently creating a stronger sense of self [52, 53]. The healthcare team should assist young survivors in identifying the impact of their experiences so that they can begin to make sense and formulate meaning. This may be achieved through interventions such as peer support groups in order to reduce feelings of isolation and facilitate integration of the survivor's experience into their identity in a positive way. Understanding how Latino AYA survivors of childhood cancer gain strength from their relationships with family and medical staff offers healthcare professionals an opportunity to have services in place to ensure a supportive environment for patients. For example, ensuring the entire extended family feels welcome as a part of the treatment process. Our findings reinforce previous results that suggest the importance of positive focus, familial support [27, 29, 31], and staff

relationships [30] for Latino AYA survivors of childhood cancer [28]. The close relationships maintained with the medical team seemed to create a therapeutic alliance and trust in the medical system that was in contrast to adult Latino cancer survivors [25, 54]. Additionally, the high level of perceived familial support seems unwavering in the face of illness similar to Sabogal's [35] findings that familism was invariable in their sample.

Although some of our results are consistent with studies of non-Latino AYA survivors, in some domains they differ significantly. Several previous studies found that non-Latino survivors felt a lack of support during survivorship [37], alienation [55], and a sense of isolation or abandonment after treatment [56]. Some of these non-Latino survivors expressed a desire to forget the cancer experience and “move on with life” and were reluctant to talk about possibility of recurrence [56]. For example, a review of Björk and colleagues [57] discovered that in their Swedish population families found it difficult to maintain high levels of familial support for the childhood cancer survivor after treatment leaving some of those children feeling “forgotten”. Their findings further revealed that none of the childhood cancer survivors in their sample reported fear or anxiety about relapse [57]. In contrast, this study's results show that the Latino AYA survivors reported a sense of continued familial and HCP's support long after treatment. In addition, these findings demonstrate a prevalence of Latino survivors' accounts of cancer remaining a part of their lives long after treatment, including a fear of recurrence. The more practitioners understand the cultural implications for Latino AYA survivors of childhood cancer the more likely they can advocate for their needs and assist these young adults to make successful transitions into adulthood as a cancer survivor.

Limitations of this study include recruitment strategy and a heterogeneous sample. The participants were recruited from a survivorship clinic where they were receiving care and continued to have strong relationships with hospital staff. Thus, participants were motivated to receive follow up care and were more likely to consider themselves part of the cancer community. The participants also varied to a great extent in types of cancer and age of diagnosis.

While a cancer diagnosis may be both a devastating and traumatic experience for young people, this study suggests that the experience may also have the potential for shaping young adults who have a positive and optimistic life perspective. It is difficult to make general statements about care for Latino AYA survivors of childhood cancers from a small group. Therefore, more studies that specifically target the Latino population are warranted. Yet, these findings indicate that there were some strengths and positive coping strategies connected with these AYA's Latino background or culture. Specifically, the importance of family, the medical community, positive attitude, and making meaning out of their cancer



experience were all culturally based coping strategies that can direct future interventions for this population.

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## Appendix A

### Interview Guide

1. Tell me about how you first learned of your cancer?
2. What does “survivorship” mean to you? How would you describe your experience of surviving cancer?
3. What are your biggest concerns or worries regarding being a “cancer survivor”? What is or would be helpful regarding these issues?
4. What do you feel your biggest strength is? What do you feel your biggest struggle is? Do you feel either are a result of your cancer experience? How so?
5. During your experience with cancer, where did you go for information and advice about...?
  - Understanding you diagnosis and prognosis?
  - Treatment and side effects?
  - Pain management?
  - Emotions?
  - Relationships?
6. How do you share your cancer experience with friends? Boyfriends or girlfriends?
7. Family often plays a big role in our world. Are their family members that helped you or not in your experience of surviving cancer?
8. Anything else that you would like to tell me?

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