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The Meaning of Surviving Cancer for Latino adolescents and emerging young adults

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Abstract

Background—Adolescents and young adult (AYA) survivors of cancer are an understudied population with unique developmental and medical needs that extend well beyond their active treatment. Survivors diagnosed as AYAs may experience both physical and emotional late effects. In particular, the experiences of Latino cancer survivors have not been explored.

Objective—The purpose of this study was to conduct interviews with AYA Latino cancer survivors to inform professionals working with these survivors.

Design—A hermeneutic phenomenological approach was selected based on the focus on experiences and meanings of Latino adolescents' cancer survivorship. Phenomenology allows for understanding the subjective meaning and lived experience of populations that are understudied or marginalized. In-depth interviews were conducted with participants

Participants—Latino AYAs between the ages of 14–21 who were all post treatment.

Results—Interviews revealed seven themes regarding the experience and meaning of survivorship for this population: gratitude, humor/positive attitude, empathy for younger children with cancer, god and faith, cancer happens for a reason/cancer changed my life/, familial support, and staff relationships.

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Conflict of Interest Summary

There are no conflicts of interest for any of the authors of this paper.

Conclusions—Latino adolescent and young adult cancer survivors develop meaning out of unique cancer experiences. Programs need to be developed specifically to address Latino adolescents and young adult survivors of cancer.

The Meaning of Surviving Cancer for Latino adolescents and emerging young adults

Cancer is a life-altering experience for anyone, but for adolescents and very young adults, the change can be profound since it occurs during a developmental phase focused on living and creating identity. Childhood cancer survival rates have steadily increased in the U.S. over the past 20 years.¹ With current treatments, 80% of children diagnosed with cancer are expected to become long-term survivors.² However, the end of cancer treatment does not indicate the end of the effects of cancer. Survivors diagnosed as adolescents and young adults (AYA) may experience learning difficulties, social stigma, poor peer relations, depression, anxiety, post traumatic stress disorder (PTSD), and difficulty transitioning to adult healthcare.²⁻⁴ Despite increasing numbers of survivors, there has been little study of the psychosocial outcomes of surviving childhood cancer. In particular, the experiences of Latino cancer survivors have not been explored.⁵ Hence, the purpose of this qualitative pilot study was to explore the lived experience of Latino AYAs who have survived cancer to provide groundwork for programmatic recommendations for improving their care.

Adolescent Cancer Survivors

According to the IOM,³ nearly one-third of childhood cancer diagnoses occur during the ages of 15–21. Adolescence is a critical developmental period and a cancer diagnosis can have significant psychological outcomes which can include depression, anxiety, PTSD, distorted self image, poor self esteem, peer isolation, developmentally incongruent fears of death, reduced social skills, and a foreshortened sense of future.^{1, 2, 5} Adolescent cancer survivors are often lost to follow-up by their pediatric clinic due to their growing independence and mobility as they enter adulthood. Consequently, this cohort has been grossly understudied.²

Despite the expected adverse psychological late effects of childhood cancer, studies are hinting at the possibility of psychological growth for survivors. Studies have found⁶ that social adjustment and educational/vocational status of young adult cancer survivors was only moderately negatively affected by illness and treatment history. In a phenomenological study of childhood cancer survivors, Karian⁷ found themes of: optimism, deeper feelings for the value of life, and an expansion of consciousness. Woodgate⁴ found some adolescents become resilient when faced with a cancer diagnosis. Key protective/vulnerability factors which facilitated or inhibited resilience were: self concept, meaning, coping, social support, and external support. Woodgate⁴ recommended qualitative studies of resilience to allow adolescents to describe the individual meaning of the cancer experience and of their survival. Since most samples are of white, non-Latino subjects, the influence of culture is unknown and warrants further study.^{4, 5}

Latino Adolescents with Cancer

Although total cancer rates for Latino non-white children/adolescents are slightly lower than their white counterparts,⁸⁻¹⁰ they do have higher rates of leukemia and retinoblastoma.⁸ When Latino children do receive a cancer diagnosis, there is evidence that they have poorer outcomes and receive more inconsistent care.⁹

Access to healthcare in general is significantly worse for Latino children than for white, non-Latino children. At least a quarter of Latino children receive no routine healthcare.¹⁰ Lack of healthcare and insurance coupled with family poverty can create significant barriers to

healthcare for adolescents of color in general.¹¹ Children with cancer from all ethnic groups are underrepresented in clinical trials.¹² Language and cultural barriers continue to present problems for Latino children to access healthcare in the U.S.¹³ Due to disparities in access to healthcare, Latino children/adolescents with cancer have been both underserved and understudied.

Latino adolescents may have a significantly different experience of cancer treatment and survival based upon cultural values. While the term “Latino” encompasses many cultures and distinct ethnicities, traditional values such as importance of family, respect for others, sense of honor, loyalty, ethnic pride, courage, and strong religious faith may deeply influence the ways in which Latino adolescents make meaning of their cancer experience as compared to their non-Latino counterparts.^{14–16} The growing number of Latino adolescent cancer survivors and the dearth of research to address their unique needs highlight the importance of this study.^{2, 3}

Because this study focused on understanding the experience and meaning of Latino adolescents’ cancer survivorship, a hermeneutic phenomenological methodology was selected. Phenomenology is an ideal method for understanding the subjective meaning and lived experience of participants specifically in populations that are understudied or marginalized.^{17, 18} Cohen’s¹⁹ approach to data analysis was used to elicit thick descriptions of the participants’ experiences and meanings during and after their diagnosis and treatment of cancer.

Method

Sample and Settings

This study was conducted at two childhood cancer survivor clinics in the southwestern U.S.: The University of New Mexico (UNM) Young Enduring Survivors’ Clinic and the Dell Children’s Medical Center (DCMC) of Central Texas LiveSTRONG Childhood Cancer Survivorship Clinic. Both sites have a 40–45% percent Latino patient population

After the study was approved by the appropriate Institutional Review Boards, purposive sampling was used to identify participants who met the inclusion criteria: a cancer diagnosis between the ages of 12–21 years old, post treatment, self-identified as Latino, and English speaking. The middle/late adolescent ages of 15–21 years were originally chosen because tumors that occur in this age group differ from other age groups and 15–21 year olds have been shown to have lower participation rates in clinical cancer trials.^{8, 20} However due to the difficulty in recruitment for this age group and the feedback from the collaborating sites, the parameters were widened to include 12–14 year olds. English-speaking participants were chosen to increase the likelihood of homogenous levels of acculturation in the study group. Exclusion criteria were: patients who had relapsed as this would change the experience of “surviving” cancer. Per Creswell,²¹ a sample size of up to 10 was projected to reach “saturation”, a point where enough data has been gathered to have complete description of the experience under study.²²

Ten participants were recruited and interviewed, 9 interviews were transcribed and analyzed. One participant was excluded because she did not have a true cancer diagnosis. Seven participants were interviewed at UNM and 2 were interviewed at DCMC; there were 7 females and 2 males and all self-identified as Latino. Age of participants ranged from 14–21 and their years since diagnosis was two to six years.

Procedures

Recruitment for the study was conducted by Latina psychosocial healthcare providers at each site. Each of these providers were psychosocial professionals, one social worker and one child life specialist, who were well known to the patient population. Potential participants were identified through clinic records and contacted to inquire if they were interested in participating. The research team members scheduled interviews with each participant and their parent/guardian (if the participant was a minor), Consent and assent were obtained from all participants.

In-depth interviews were conducted with each participant and lasted approximately 1–2 hours each. The interview guide was developed by the PI based upon review of the literature of meaning-making and childhood cancer, specific study aims, clinical experience, and feedback from co-investigators. Using a phenomenological approach to interviews, the subjects were asked five open-ended questions about the experience and meaning of surviving cancer. Probes were used to open up further dialogue between researcher and subject. Interviews were conducted by the PI, co-I and a doctoral student who were all trained by the PI in qualitative interviewing skills. Interviews were audio taped and transcribed.

Data Analysis

Interview data were analyzed inductively using an ongoing iterative process outlined by Cohen, et al.¹⁹ The first step in analysis occurred as data were collected, while interviews were conducted. This step included active consideration of the meanings conveyed by the participants and possible labels for those meanings. Tentative understandings were recorded and continually refined as the analytic process continued throughout and beyond data collection. The process of “immersion” in these data continued as the research team carefully read through the data several times in order to gain an overall sense of the participants’ experiences. This was followed by data reduction, in which the data were reviewed to identify material relevant to the study aims. The next phase, thematic analysis of the data, involved the identification of common threads or concepts that linked individual participant experiences together. This process entailed careful, line-by-line review of the interview texts for phrases and themes that represented an important aspect of the participant’s narrative. Efforts to promote trustworthiness of the findings included use an audit trail, use of Latina co-investigator and a co-investigator experienced in oncology research and hermeneutic analytic approaches, all data and coding decisions were made in consultation with the co-investigators.

Results

The data revealed seven themes that were salient for these Latino adolescent cancer survivors: *gratitude, humor/positive attitude, empathy for younger children with cancer, god/faith, cancer happens for a reason/cancer changed my life/, familial support, staff relationships.*

Gratitude

Participants expressed a sense of gratitude for others who had helped them through their cancer experience. As one adolescent indicated,

“I felt a lot of gratitude because so many people took so much time out of their lives but they didn’t have to. Nobody really had to be there. And they were without a question.”

Many participants expressed that cancer made them focus on how precious life is,

“I guess you appreciate everything that people do for you. You just have a different view on life than you did when you walked in. You really do, because you know when

everything is in jeopardy, you really have to figure out what you want because every second that you waste is wasted. And you don't get it back."

Humor/Positive Attitude

Participants indicated that humor and a positive attitude were important aspects of healing. One young woman stated, "Being Latino we tend to take things lighter. We always find humor in something." Similarly, another told how she used humor in the hospital,

"Yeah I used humor. After they give shots with those things you put in your mouth and it makes your mouth glow, my sister and my friend, they would put them on and go to the window because one of the other rooms you can see into and they'd stand and we'd turn off the lights and they would make faces and people there would be like ahh ...what's going on in their room? "

Many of the youth interviewed indicated that having a positive attitude helped them survive emotionally. For some, this meant not focusing on the lethality of the diagnosis, "I always knew there was a possibility (of dying) but that's not what I focused on. It was just something that I have to go through" Another participant said,

"And then you remembered that there is something inside of you that could kill you and I think that's one thing that I could never comprehend that there's actually something that could kill me. I never thought of it like that, I always thought, no I'm always going to be fine. It's nothing."

For other participants, healthcare professionals helped them find this positive attitude,

"Doctors helped me out. They told me that the more positive attitude you have about it, the better you heal. If you stay down and depressed and beat yourself up over it, you won't heal as fast. Treatments are harder. So it's all about being positive. So I was positive, always looked at the good side about things. "

Empathy for Younger Children with Cancer

Almost all participants indicated that they had strong respect and empathy for the younger patients. One participant stated,

"The people that are the true survivors are the younger ones. Because I couldn't imagine being that young and then having cancer on top of it, and not being able to understand it. When I think of the cancer survivors I think more or less of the little kids because I've seen babies with it and it hurts so much to see little kids."

Another participant stated,

"I think in the beginning I was so bitter. I was so angry because my thoughts were why? Why me? What did I do that was so horrific that I deserved to have this done? And I actually didn't get an answer until I saw little kids that were sick, and it's like how can I say that? How can I say why me? Why not me? Why? What makes me so much more special than these little kids? "

God/Faith

Faith was an important part of coping for many of the young people interviewed. For some, this faith was a return to an earlier belief system, "I found myself praying constantly for something We take for granted things until we need something—until something bad happens. And then we feel like praying." For others, God had been an integral part of their lives and that connection grew in this crisis,

“I come from a really strong Catholic family and so you pray to god. Don’t worry. It’s going to be fine, it’s in god’s hands, I was always very focused on my faith. And so it never really occurred to me that you know oh I’m going to die.”

For others, their families’ beliefs helped them as well,

“My mom, she actually took me to church and we just prayed and she’s like- it’s going to be okay, you know, it’s just a setback, you’re going to be fine. Nothing to worry about, you know. It’s in god’s hands, you’re going to be fine, I can feel it. You’re going to be okay. And it’s just reassuring, you know. Because you have your own thoughts but to be able to just go yeah, it’s going to be okay, it’s going to, you know?”

One young woman, described in some detail how her family now makes a walk to Chimayo, an expression of faith that previously had not been important to them but now is a source of family bonding and faith,

“We walk from Santa Fe to a little church called Chimayo, They have holy dirt and it is supposed to cure the sick. And so you’re supposed to make a pilgrimage to Chimayo so people get there around midnight, you know, to make it there on Good Friday., And when I got chemo treatment that first year, we did that, and we all walked. And now we walk every year.”

A number of participants stated that cancer affected their faith,

“Before this, I knew about God and the saints but I didn’t care. I had stopped caring about my faith, actually. And when this happened people would pray over me all the time. I’d find myself going to church just to feel calm and being able to just to reflect on things. I mean because when I first started all of this I did question a lot about God, and why all this, and why me, and just everything was really chaotic. My mom told me people never think of god when they’re not in trouble, but when they are that’s when they find him. That’s very true because throughout my life I might have prayed once or twice, and during this I found myself praying constantly for something and just having her say that made a lot of sense - we take for granted things until we need something—until something bad happens. And then we feel like praying.”

Cancer happens for a reason/ Cancer changed my life

Many of the participants in this study indicated that they believed that cancer happened to them for a reason and changed their perspective, attitudes or behavior for the better. One young man stated, “I used to be very angry. And now, I don’t let people bother me. I don’t let people make me angry. People have their opinions about me, that is their opinion. I know who I am; I know what I need to do. “Another participant stated,

“Now I’m in college. Before I just went to school, but it was just something to do. It’s something to fill up my day. But it wasn’t very important to me. Cancer showed me how precious my life was. And I really agree that it was something that needed to happen. Because even though nobody told me things, they all felt it- that I wasn’t on a good path and they just didn’t know how to get me off.”

While they may not have wanted to have cancer, these adolescents were able to find some meaning out of being sick, “I think I needed it. I think it was something that I had to experience in order to get to where I am.”

For some, the meaning took the form of better relationships and priorities,

“I was headstrong. I thought I knew everything, I thought knew what was good for me, what friends I really wanted in my life. And actually that was really wrong because all the people that I called friends, when I’ve gotten sick only one of them came. And

these were people that, oh we got your back, you know we're going to always be there, don't worry. And nobody came. The people that I held higher than my family couldn't care less; yet my family was here without a question. And that really opened my eyes 'cause it just made me realize about the person I was becoming. And I realize that's not who I wanted to be."

For other participants, cancer reduced their risky behaviors,

"I think I would have ended up, I don't want to say messed up or...but the people that I was hanging out with and the way that I was behaving, I would have ended up either raped, murdered, something bad would have happened to me because I didn't care enough to think about the situation. I didn't care enough about myself to really say this really isn't the best, you know? I don't think I should be here, I don't think I should be where I was. Because it was on the track to being that way."

Many adolescents expressed a priority shift about what was important in life,

"I don't like to complain, because no matter how much, how bad life is, it will never be as bad as that. And I think you kind of lose perspective of how bad a situation is. It's really funny how people view things, because you know 3 or 4 years ago if somebody would have messed up my hair, it would be the end of the world. I could cry for days. And now nothing really fazes me anymore."

Some adolescents said that cancer made them kinder,

"I was that mean girl in class who didn't talk to people because she thought she was too good. I was too good to be someone's friend. That wasn't what I could do with my life anymore. And I think I'm a better person because of that."

And others recognized that they had to grow up quicker than their friends,

"I think it made me grow up when I was real little, and that was kind of hard because I was barely approaching high school. So I didn't really get to have those years where I could do whatever I wanted to just be at home or go to school or not go to school, you know?"

Another put it this way, "I think I am better, I really do. Just because, for me, personally, when I got sick, I really had to grow up. I think I was already kind of mature, maybe just right for my age, but at that point I really had to grow up". And yet another participant stated, "In a way it shoved me into adulthood as much as I didn't want to go. And I don't think my experience with my cancer or my diagnosis has made me bitter." Some participants went as far as to say,

"I wouldn't have changed the experience. I think it changed everyone in my family, not just me. But when I first got cancer, I was already kind of depressed. I had to really get out of that because that wasn't the time to be depressed—had to be fighting and so... I just learned that I wanted to be healthy and like myself more than I did because if I didn't I wasn't going to try so hard to get better, you know?"

Familial Support

Another culturally congruent finding was that participants relied on family support to help them get through their experience. One said, "I was never alone. I would go in there and I had at least 7 people with me. I had my mom, my little sister, my best friend, and my step-dad." And another,

"Well as for the chemo part, you know, I had my mom, my sister, my ex-sister-in-law and my friend. They would basically make the trip with me and stay four days in the little hospital rooms with me."

And a third participant,

“There was no hesitation for my family. There was never, ‘I can’t.’ It was always, ‘We’ll find a way. Don’t worry. It’s okay.’ There was a lot of times they would stay with my till 2:30 in the morning. There was never a feeling that they didn’t want to.”

Family support, including extended family, was a consistent theme,

“One time they told everybody you should come down - they had bad news and that’s when they had found out it was cancer. And basically my entire family showed up. Just to make sure that I didn’t freak out. And so I had all my uncles, all my grandma’s brothers -they came down.”

Family was present and connected to these children, “There was always somebody there with me. I was never left alone. Even with my sister who would just actually crawl into bed with me and just lay there. I always had someone with me.” For some, they even felt that they got closer to certain family members, “Well my dad and I, we were very close all the time from when I was little. But, I think more so after I got sick.”

Staff Relationships

The participants in this study indicated that the staff members were very important for them,

“Doctors. Nurses. The social workers... They were always so positive. Always. They always talked to me very comfortably, and even if it was a bad situation, they still put it in a very good way. They were there to comfort me and there was always a bunch of doctors around. So they were very helpful. And there were a bunch of good people. They were my second family.”

For some the hospital was a positive environment,

“I like coming for appointments because I see all my doctors and those people that became friends after a long period of time. That’s kind of weird because, you know, most people don’t like to go to the hospital when they’re sick. But, for me, it was okay, everyone’s here that knows what to do. All the medicine’s here, the doctors are here. Anything bad happens-I’m going to be okay here.”

Implications

Creating services for Latino adolescent cancer survivors—The results of this pilot study highlight the importance of family, community, communication, and faith for Latino adolescent cancer survivors. The seven original themes that emerged for this population were *gratitude, humor/positive attitude, empathy for younger children with cancer, god/faith, cancer happens for a reason/cancer changed my life/, familial support, staff relationships*. While larger samples of this population and cross-comparative studies of other ethnic groups are needed, these results do provide opportunities for healthcare professionals to begin to address this group of young people, both those who are on treatment and those who are finished with treatment. For example, understanding how Latino AYA survivors value family can provide opportunities for health care professionals to include the entire extended family throughout the treatment process. These findings also suggest that this group of young survivors are making meaning out of their experience and integrating that meaning into their understanding of relationships, values, and faith. The health care team can and should engage Latino AYAs in conversations about the experience of cancer and how it impacts their self identity, relationships and understanding of the world around them. These conversations can begin upon diagnosis and continue throughout the treatment trajectory and beyond. Helping this group of young people identify specifically how they have been impacted or changed may serve to help them cognitively organize the experience and begin to make sense out of it. Ideally, these

interventions can be combined with peer to peer support so that there is reduced isolation and opportunities for increased self image.

Another finding that can have implications for the treatment team is that Latino AYAs expressed appreciation for humor and levity in the midst of the treatment. Healthcare professionals can utilize their own humor and engage this group of young people in identifying opportunities for natural humor, while continuing to be empathic to the difficult reality of childhood cancer. Importantly, this group of survivors spoke very highly of the relationships that they had with staff and how those relationships positively affected their experience of treatment. Health care providers should recognize that forming positive, supportive relationships with these young people provides an emotional healing that is long-lasting and crucial to their future growth. Young survivors remembered the moments of support and humor and caring that professionals provided as they dealt with their cancer diagnosis and treatment. Regardless of the treatment roadmap, prognosis or outcome, providing support and relationships can ease the suffering and help adolescents know that they are cared for. This caring can help them cope with the treatment and effects of cancer.

Implications for Post-Treatment/Survivorship—Many of the participants in this study indicated that they did not see themselves as a “survivor” and often equated that label with the younger children they saw in the clinic. Further exploration is necessary to understand whether the adolescents were discounting their own experience in comparison to the children or if the label “survivor” was just not congruent with their identity. Another possible factor is that many of these children were treated before the term “cancer survivor” was used freely and before the development of specific integrated clinics to attend to this population. These findings do suggest, however, that the experience of surviving cancer for Latino AYAs may present unique opportunities for targeted intervention. Programmatic improvements could include providing a separate space for teenagers to be treated such as free-standing teenage oncology clinics or separate treatment spaces. For clinics where children and adolescents are treated together, adolescents who express interest in the younger children could be encouraged to take on a mentoring or supportive role in the clinic setting.

For these adolescents, the cancer changed their lives and continues to influence them today. The phrases used to describe this experience included, “cancer changed my life”; “I’m glad I had cancer”; “Cancer has made me a nicer person”; “Cancer saved me from a bad path”; and “Cancer made me who I am.” Most of the adolescents were quite clear, however, that the experience was difficult, traumatic, and beyond their expectations. However, after the treatment, many could insightfully reflect on the meaning of the experience and how it impacted them. Some discussed their current careers in healthcare as direct outcomes of having cancer as an adolescent. There is a growing body of literature in the areas of meaning-making and post-traumatic growth that could be consulted in programming in pediatric oncology clinics. Perhaps identifying the factors that facilitate a positive attitude and sense of meaning could guide how teams help adolescents cope while they are undergoing treatment and beyond. Incorporating opportunities for adolescents to reflect on their experience during and after treatment are critically needed.

Cultural implications—It is difficult to extrapolate the findings from this small group of adolescents to make general statements about care for Latino adolescents. More studies that target specific ethnic populations are warranted. When asked directly, these participants did indicate that there were a few coping strategies that they believed to be connected with their Latino background or culture. Specifically, they indicated the importance of family, community, faith and humor as all culturally-based coping strategies. These findings are congruent with other studies of Latino adolescents that highlight the importance of the family, spirituality and community.

Discussion

Given that there are a growing number of adolescent and young adult cancer survivors in the U.S. today, it is likely that these young adults will present for care in general practice settings. While some adolescent and young adult cancer survivors may choose to follow up their care in a designated cancer survivor clinic, this will not be possible for the nearly 270,000 childhood cancer survivors that will need to be medically followed.^{1, 23} Particularly underserved are communities of color who disproportionately experience health care disparities and reduced access to health care. Understanding the issues that are important to this unique patient population can help the physicians, nurses and social workers in oncology and non-oncology settings provide more tailored and culturally relevant care to increase the likelihood of growth and health promotion. Since many of the young people interviewed indicated that their cancer diagnosis changed their lives and yet, they do not consider themselves “survivors”, it is important to assess for previous history of cancer in young adults and to provide opportunities for them to indicate how this impacts their health and life in the present.

There are guidelines to assist the general practitioner in caring for adult survivors of adolescent or young adult cancers. The Children’s Oncology Group has produced *Long-term Follow up Guidelines for Survivors of Adolescent and Young Adult Cancers*, a risk-based set of clinical guidelines, that provide recommendations for assessment and management of late effects of adolescent, and young adult cancers.²² In addition, the NCI and Lance Armstrong Foundation produced, *Closing the Gap: Research and Care Imperatives for Adolescents and Young Adults with Cancer* in 2006 which included 5 overarching recommendations to guide the work of the AYA advocacy community:

1. Identify the characteristics that distinguish the unique cancer burden in the AYA patient
2. Provide education, training, and communication to improved awareness, prevention, access and quality cancer care for AYAs
3. Create the tools to study the AYA cancer problem.
4. Ensure excellence in service delivery across the cancer control continuum
5. Strengthen and promote advocacy and support of the AYA cancer patient.

In order to improve care for this group of patients, all parts of the health care system must be engaged in understanding their unique experiences.

Adolescence is a unique developmental period that is focused on independence, identity-formation, social groups, and future life plans. When an adolescent receives a cancer diagnosis during this time, the focus shifts to survival and the young person can become quite isolated and adrift from their typical developmental tasks and experiences. A cancer diagnosis creates the uncertainty of living with the fear of death. Living with cancer can change adolescents as they are growing into adults and developing their selves. What is not yet known is exactly how this impacts differing ethnic groups and different stages of AYAs. It does appear however, that the potential for improving outcomes is present and that programs need to be implemented that capitalize on this opportunity for growth. Nurses, social workers and health care professionals can play a key role in promoting long term health and wellness for Latino adolescents and emerging young adults who have survived cancer.

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