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Pediatric Cancer Patients' Treatment Journey: Child, Adolescent, and Young Adult Cancer Narratives

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ABSTRACT

Purpose: The National Cancer Institute has acknowledged that for children, adolescents and young adults (AYAs), cancer is a leading cause of disability and death. This population has unique needs and until we fully understand those needs, we will not be able to provide optimal care. The purpose of this study was to understand the self-reported experience of cancer according to children and AYAs.

Design and methods: A qualitative descriptive design was used. After obtaining IRB approval, participants were interviewed in Spanish or English. Thirty interviews were conducted with children and AYAs ages 10–22. Questions were asked about the patient's treatment journey and the impact on their lifestyle. The interviews were recorded directly in digital audio files, then transcribed using Verbal Ink®. Themes were derived after the data were organized using Dedoose® and then coded.

Results: Children and AYAs described the cancer experience as difficult due to activity challenges and disconnection from school. Patients noted that their physical inactivity led to deconditioning. Children and AYAs reported storytelling as a way to cope with newfound disabilities. Patients reported that their illness allowed them to build closer relationships to family. Feelings on other issues arose, such as communication challenges experienced with transition from adult to pediatric hospitals. The value of altruism emerged as a way to provide purpose in their journey.

Conclusions: Children and AYAs have particular concerns that the healthcare community needs to address. These qualitative findings have specific recommendations for practice.

Introduction

In 2018, the National Cancer Institute anticipated 15,590 new cases of cancer diagnosed in children and adolescents under the age of 19 years in the United States (Siegel, Miller, & Jemal, 2018). Although pediatric cancer long-term survival is improving with 80% of children cured of their disease, those aged 15–29 have not shared the same improvement in cancer survival. For acute lymphoblastic leukemia, the five year survival was 91% for children younger than 15 years of age compared to 74% for young adults 15–19 years of age (National Cancer Institute, 2017). In addition, there are still many treatment-related consequences that cancer patients' encounter during and after treatment. One deleterious consequence of treatment for the pediatric cancer patient is psychological trauma resulting in post-traumatic stress disorder (PTSD), which can lead to short-or long-term mental health issues (Norberg, Pöder, Ljungman, & von Essen, 2012). The nursing discipline is uniquely positioned to intervene by integrating a holistic approach to healing the body, mind, and spirit of these young patients.

A cancer diagnosis has a significant impact on the evolving life narrative of children, adolescents, young adults (AYA) and their families; therefore, it is prudent for health care providers to hear their stories. Qualitative description research provides a vehicle to understand the cancer journey and may be useful in learning the who, what, and why of their lived experiences (Neergaard, Olesen, Andersen, & Sondergaard, 2009). Having a clear understanding of the perceptions and experiences of children and AYAs with cancer offers health care providers (HCPs) an opportunity to develop an individualized supportive treatment plan that best fits the patient and family. Qualitative

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research offers valuable insight to understand patients' reality, minimizing trauma, improving quality of life, and perhaps improving physical and mental health outcomes.

Purpose

The purpose of this study was to utilize a narrative-based medicine intervention to explore the self-reported experience of pediatric and adolescent cancer patients and analyze these stories in relation to three primary paths of inquiry: 1) what does the cancer diagnosis and experience mean to the children and? 2) what are the interventions and resources that help the children and during diagnosis and treatment? 3) what are the barriers that interfere with healing and coping with cancer for these children and AYAs.

Design and methods

Setting

This exploratory-descriptive qualitative study was conducted in a freestanding, 279-bed tertiary care children's hospital located in southern California. The Hyundai Cancer Institute has approximately 200 newly diagnosed cancer cases annually. The center provides a variety of different treatment options for cancer patients, including: phase one chemotherapy, radiotherapy, immunotherapy, and bone marrow transplantation. There is a 28-bed inpatient hematology/oncology unit, an overflow unit, and an outpatient center, which includes the outpatient clinic and infusion center.

Subjects

Thirty participants were recruited for this single-center study. Participants were recruited using convenience sampling from the pediatric and AYA patient population. Inclusion criteria were broad so as to increase transferability of findings, and included children, adolescents and young adults, 10–25 years of age, diagnosed with any cancer. Participants were either receiving active treatment or had completed treatment for their cancer within the year prior. Participation was limited to patients fluent in either English or Spanish. Potential participants were excluded from the study if they were deemed intellectually impaired and incapable of completing the study requirements, or too ill to complete the interviews.

Institutional Review Board (IRB) approval was obtained prior to study recruitment and prior to initiating study procedures. All interested participants were provided written informed consent or assent prior to start of the story telling process. For those less than 18 years of age, written informed consent was obtained from one parent or legally authorized representative of the patient.

Interviews were conducted with eight females and 22 males ages 10–21 years (Table 1). There were five children ages 10–11 years, five AYAs ages 13–14 years, ten AYAs ages 16–18 years, and ten AYAs ages 19–21 years. Cancer diagnoses included 24 patients with acute leukemia (80%) and 6 patients with solid tumors (20%). In addition, four of the young adult participants had experienced multiple relapses. Eighteen interviews were conducted in English (60%), and twelve interviews were conducted in Spanish (40%).

Procedure

Investigators used semi-structured interview guides to elicit narratives about participants' experience with cancer. Various studies were reviewed to develop the guides (Lewis, Jordens, Mooney-Somers, Smith, & Kerridge, 2013; Portnoy, Girling, & Fredman, 2016; Woodgate, 2006; Zebrack et al., 2013). Questions were developed based on themes previously identified in the literature. To facilitate rigor, the guides were developed to promote trustworthiness based on Lincoln and Guba's (1985) classic work on naturalist inquiry. Prompts were designed to promote compassion and empathy during the interviews to establish rapport between the investigator and the participant, and ensure credibility as well as participant comfort in sharing their truth.

Table 1
Demographics of study participants.

Characteristics	Details	Number
Interview language	English	18 (60.0%)
	Spanish	12
Sex	Males	22 (73.3%)
	Females	8
Age	Range (years)	10–22
	10–11	5
	13–14	5
	16–18	10
	19–22	10
		Mean 16.46
Disease	Leukemia	24 (80.0%)
	Solid tumors	6
Ethnicity	Hispanic/Latino	19/30 (63.3%)
	Multiple Races	3/30
	Caucasian	4/30
	African-American	1/30
	Asian	2/30
	Middle Eastern	1/30

The encounters between one of the three investigators and the participant lasted approximately 30 min and were conducted in a quiet private room, in the preferred language of the patient. Participants were given the option of having a family member stay with them during the interview, though family members did not contribute to the interview session if they were present. The investigator began the session with demographic questions, followed by directed questions from an interview guide aimed at eliciting the patient's narratives about school, extracurricular activities, and the impact cancer had on their psychological, emotional and social lives. To direct the patient narratives, three primary paths of inquiry were pursued: 1) what does the cancer diagnosis and experience mean to the children and AYAs 2) what are the interventions and resources that help the children and AYAs during diagnosis and treatment? 3) what are the barriers that interfere with healing and coping with cancer for these children and AYAs?

Data analysis

Computer programs were used to assist qualitative data collection and ensure systematic data analysis. Interviews were recorded directly as audio files onto a laptop computer, transcribed verbatim using Verbal Ink™, and then reviewed for readability. Interviews conducted in Spanish were first translated by one of the co-investigators and then transcribed. The transcripts were analyzed in detail by each member of the investigative team in search of emerging themes within the narratives to understand the lived experience of the patients. Peer evaluations were employed to enhance credibility of the findings as the data were analyzed. All transcripts and de-identified data were stored via Dedoose™, a storage program for qualitative and mixed methods research. This program was used to objectively transcribe the data to allow for more detailed analysis and theme identification. Reflective notes were recorded on the manuscripts to assist with thematic confirmation. Consensus about the themes was achieved by discussion between investigators. Investigators included international expert AYA oncologists and nurses. Data were not analyzed to compare variances in developmental ages, gender or ethnic diversity.

Results

Saturation of data was reached with 30 participant interviews. Two main themes emerged: activity challenges and disconnection from

school. Subthemes included: the importance of storytelling, building relationships and overcoming isolation, and the value of altruism towards patients in the future. This section presents summary findings related to these questions with specific quotes from the patients to aid in confirming the interpretations of the authors.

What does the cancer diagnosis and experience mean to children and AYAs?

The consistent areas of concern related to what the cancer diagnosis and treatment meant to the patient were 1) activity challenges attributed to cancer treatment; and 2) alternatives to regular school attendance.

Main theme: activity challenges

All participants identified having activity challenges attributed to their cancer treatment and hospitalizations. Participants commented that before their cancer diagnosis, they did not have to think consciously about their activities of daily living or what a typical day would look like, as they had no physical limitations. The participants talked about how their diagnosis radically changed their perspective on daily activities that they had previously taken for granted. Participants reported loss of strength as well as inability to participate in preferred sports secondary to cancer treatment and precautions. The recurrent theme of limited physical activity was well-stated by one person as, "I am definitely not what I was, in terms of my 'old physical self'". Other similar sentiments include:

> "I can't run. I can't walk because of the medicine I take. I need to learn to walk again. I am out of breath. I can't do [physical education class] because my legs are weak. I'm trying to get them strong" (13-year-old male);

> "Well, I used to run, not walk, before my cancer. Now [that] I have cancer, I walk crooked-like and cannot walk with the other kids anymore" (11-year-old female):

> "I used to play volleyball in high school, and I grew to love it. Now that I have avascular necrosis and I can't really move much from my waist down, it's very frustrating that I can't go out and do this thing that I love" (22- year old male).

Not all patients were focused on their limitations or disabilities; some were more proactive with their own physical recovery. Others used support systems to help with accommodations to manage their physical challenges and help get them back into regular activities they did prior to their diagnosis with cancer.

> "Well, I'm on the varsity cheer squad for this year, I cheer at the games. We have boxes and stuff like that, but I cannot stand on it because of my legs. So, I sit on the box and do the cheers instead of getting up and doing them. The team needed to remake the uniform, so I could participate" (16-year-old female).

Young adults in the study (N = 10) wanted to combine social events with more physically active games, allowing patients' to be more active while still having opportunities to meet other patients.

> "I think the cancer program is really great, but I would create more physical activities that could help the patients' be better physically, and at the same time, create more chances for patients to meet together. [When they] talk to one another they learn more about other's experiences and comfort each other on our journey" (16-year -old male)

Most patients appreciated help from nurses to be more active by engaging in physical activities.

> "I was supposed to do my [incentive spirometer] every hour and I never did it. She set a timer on her watch, walked in, grabbed it, set it in front of me, sat down next to me and said, 'I'm not leaving until you get to [this line] right there, twice" (19-year-old male).

The loss of physical activity, and thus diminished physical strength, was reported by 22 participants. Common narratives emerged around regret and "if they only knew how cancer was going to affect them, they would get out of bed every day and try to maintain physical strength". Many patients had lost their ability to dance, sing, walk or run long distances. In answer to the prompt, "What would you change…", participants stated they would want more encouragement to do some physical activity each day.

Main theme: disconnection from school

The inability to attend school while receiving treatment was problematic, resulting in the patients' attending one or more alternative school settings during treatment. Loss of school meant both loss of peers and the loss of teachers as mentors. School is often the center of a child's life that provides routine for the child and the family. The relationship between school and family life is completely disrupted during the phases of cancer diagnosis and treatment.

One young man talked about how he would stay after school to work on cars in the auto shop. After he was diagnosed with cancer, his auto shop experience was over, and he "bummed about the loss". Conversely, some students coped well with changes in their school attendance and reported that their grades were affected in a positive way. They had more time to finish their schoolwork during treatment. Other students had significant struggles with the loss of this huge part of their life. They spoke about loss of connection with both peers and teachers.

In interviewing patients about the impact of cancer treatment on school attendance, 25 patients reported that their cancer diagnosis and treatment disrupted their ability to attend school. Of these patients, ten participated in a home-school program in conjunction with their traditional schools while in and out of the hospital. Even with homeschooling, inability to focus and difficulty concentrating was reported. Five children completely withdrew from school to participate in cancer treatment. Nearly half of young adults (14/30) participated in a home-school program for high school during treatment, and half of those (7/30) graduated from high school by self-report. Five young adults decided to drop out of college and had not returned to school at time of the interview.

Overall, the patients considered school attendance as a challenge because they had problems concentrating, they suffered from fatigue, and they felt separated and isolated from their peers. They were anxious about their health status and wondered if it would get worse with class attendance. They worried if they would feel well enough to attend each day, and if did, would they be able to concentrate on their schoolwork.

> "I was home-schooled in my junior and senior year in high school. My second year of college I had to drop [out]. It's harder for me to focus on things. They said there is the 'chemo brain'; I had it" (21-year-old male).

One 19-year-old said "it's harder to focus with chemo brain". He also commented that the loss of the high school experience and anxiety about being with friends made him reluctant to go back to school. Five other young adults continued with college, but complained that "chemo-brain and the loss of the overall high school experience made it hard to connect to new friends." Young adult patients attempting to attend college found they needed to drop classes to make appointments and go to treatments. Many times, patients found that the impact of their diagnosis stretched past the practical aspects of attending school and into the social consequences of missed time with friends.

Despite the isolation, some patients still managed to make the best of their opportunities. One young man spoke of the connection he made with his teachers during treatment that helped him accomplish his dream of going to college. Two teachers made a major impact by writing letters of recommendation for scholarships.

> "A lot of scholarships ask that you volunteer... So hopefully I'll go around the world give speeches and visit children in the hospital" (17-year-old male).

One patient, who did not speak English when she was diagnosed one year prior, had gone on to graduate as valedictorian of her English-speaking class.

> [*valedictorian*] "*School has always been important to me. A teacher came and she helped me. The work she brought me wasn't too much and I was able to do it*" *17-year-old female*).

What are the interventions and resources that help the children and during diagnosis and treatment?

Subtheme: the importance of storytelling

A significant resource to help children and cancer patients manage their emotional and spiritual struggles was the use of some method to document and remember their cancer journey and ease the burden of the cancer journey. Approximately three-quarters of patients reported using photographs to document their journey to remember aspects of their treatment as well as those they have encountered on their journey. Given the easy access to cameras via cell phones, the widespread use of a photo narrative was not surprising. Ten participants tracked their cancer journey via Beads of Courage®, an international resilience-based intervention program that was developed by a nurse and utilizes a collection of beads to document each event, milestone, procedure and treatment (Chart 1). Eight participants used a memory box that included all objects related to treatment, including actual removed central venous catheters. Three patients wrote journals, five patients used music and six patients shared their story in a college essay or at a public event.

Chart 1
http://www.beadsofcourage.org/pages/beadsofcourage.html

Beads of Courage® (BOC) was developed as an arts-n-health program to strengthen resilience and facilitate coping in children diagnosed with cancer (Baruch, 2002). BOC is a system of visually representing the experience of children undergoing cancer treatment and serves as a medium through which children can tell their stories. The BOC program involves the use of beads, a tactile art form that nurses give to children who are diagnosed with cancer to help tell their story of their cancer journey. The colorful BOC program beads are stored in bead boxes, which are located on the inpatient and outpatient clinical areas. Each bead corresponds to a specific treatment, for example, red beads are for blood transfusions and white beads are for chemotherapy treatments.
The Beads of Courage® program uses specialized beads awarded throughout each part of cancer treatment, such as accessing ports to days of physical therapy, to major accomplishments like completing treatment, getting radiation therapy, or having a bone marrow transplant. Collected beads are strung together in such a way that the patient's journey can be visualized by the sequence and number of beads. Many patients' collected multiple strands of hundreds of beads, allowing them to tell the story in a more visual, tactile, and unique way.

> "I have a lot of [hospital} bracelets, a lot of visitor passes. On my closet [door], I have a bunch of bandages. I have the cast from the Broviac and the ones they change every week. Right now I am going to pick up my port; I just got it out. I have a bunch of Beads of Courage™. I had that many chemos; I had that many transfusions, knowing that I made it. It has a positive ending" (19-year-old male).

> "Yeah, I do music. I haven't written a song about the subject. Soon I am … cause this whole process is over all I'll say, this is a memory box that's in my head. I have been thinking about songs, cause writing music for me is therapeutic" (19-year-old male).

Some participants wanted to share their story to inspire others. Others wanted to keep a record of their journey so they could look back at their story as they moved forward in their lives.

> "I write a journal on my computer and keep track of the daily 'everything' that happens. I have been doing this for the past month. I want to look at it in the end and see just what I went through. In the future, I want to go to medical school, so I can look back on this experience to help me for in my essay" (17-year-old male).

Of note, four participants stated that they did not want to remember their journey. These patients preferred to forget about their cancer experience, despite creative and narrative opportunities presented to them.

There were other aspects of the patient's care that emerged as a helpful intervention to ease the burden of their cancer treatments. For example, receiving their healthcare in a pediatric hospital was consistently reported as helpful, even from patients who started treatment in an adult hospital.

Staying connected to friends is a challenge that is handled differently by different age groups and personality types. Even though social media and technology seem like logical tools for children and AYAs to connect with others, the patients' attitudes towards social media and technology were divided. Two patients felt Facebook and Skype were tools to facilitate connection, where others thought it was a reminder of what they were missing.

> "I remember when I was diagnosed I was very mad at the world because I was in the hospital with a bunch of other kids and teens and we were having the worst time of our lives, and I would log onto Facebook and I would see that this person went to this concert, and that friend was at Disneyland and I am sitting here with venom in my veins, and I can't do anything about it" (22-year-old male).

Two patients described how psychologists helped manage their perceived fears.

> "I had this irrational fear that the doctors' and nurses weren't telling me everything. The psychologist would come and talk to me, be more assuring of everything that's going on, and how everything is playing out, and be open to whatever the patient is feeling." (22-year-old male).

Two patients described how faith in God gave them strength.

> "I always trust in God, even though they told me you only have a 20% chance of living and [the cancer] has invaded your body and we don't know if the chemotherapy is going to work. I always said I have to move forward and I know I will move forward with God's will and God's hand. And thank God, I'm here three years later, with the cancer, but I've known to get through it and survive" (20-year-old female).

Other patients were more creative about their means of communication.

"In the PICU, I remember a wand my grandma gave me, which we called the 'Crapper Tapper'. I was intubated. I used the tapper and my iPad to help me talk" (19-year-old male).

What are the barriers that interfere with healing and coping with cancer for these children/adolescents/young adults?

Subtheme: building relationships and overcoming isolation

Both children and AYA patients reported that their cancer treatment disrupted their lives. In the interviews, they described the experience of cancer treatment as difficult. Having contact with other kids their age was clearly a priority for them to help meet their unmet needs.

Relationships with family and friends were somewhat paradoxical for this group. In general, older participants noted a change in the scope and breathe of their social circle, in that their social sphere became smaller, but consisted of deeper and more meaningful friendships. Most participants reported that close peer and family relationships were stronger. Across the age span, patients stated their relationship with their parents made them stronger. However, they also reported feelings of social isolation from disconnected friendships and people not really supporting them as they had expected.

"It's pretty much changed. I don't really go outside. I only go to my friends' houses when they invite me over or have something planned. I don't really go out and do stuff. The only thing I go out for is school or appointments" (16-year-old female).

Subtheme: communication challenges

Twelve patients reported specific communication tactics that were not helpful. They consistently report that inappropriate, inadequate, or nonexistent communication was not helpful in their understanding of their disease and recovery. One AYA female expressed her frustration over talking "baby talk", and in addressing her parent but not addressing her directly.

"I needed positivity, not baby talk, like 'We are going to check your tummy,' or 'Did you go potty?' You feel like you are being patronized. I know that's not how they mean it. And please don't ask my dad how I am doing; ask me" (20-year-old female).

This AYA male expresses well the stigma he perceives with the diagnosis of cancer.

"People would treat me the same as if I'm not sick, and that would help me. Because once people find out that I have cancer, they treat me differently. They look at me as if I am made of glass" (19-year-old male).

Subtheme: the value of altruism

During the interview process, as young adults shared their unmet needs, researchers uncovered an underlying sense of altruism towards patients in the future. They used the experience to learn about themselves, transform their own life, make a future for themselves, and make the cancer experience better for those that followed.

"*I see this cancer…this illness as a bump in the road that allows you to learn things about yourself that you didn't know before…So what it did was give a clear picture of who I am, what I want, and what I'm supposed to do to get there…Trying to help others was also a big part, telling myself that when I get through this I'm going to help whoever I can. Whenever they feel like they're in a situation where they can't, they don't know what to do, or they can't see the end of it... So that's what got me through*" (*22-year -old male*).

Discussion

The present study employed qualitative descriptive methodology to understand the self-reported narrative experience of children and AYA patients in their cancer journey. Institutions and health care providers can use this information to design interventions that address the needs of patients and families dealing with childhood cancer. Interventions that patients found helpful in coping with cancer and treatment were reviewed, as well as those barriers that interfered with healing.

The most consistently identified and significant impact of cancer treatment on the participants was on activity challenges and disconnection from school. The importance placed on this loss in physical abilities as compared to their peers suggests the significant impact that had on their perception of their own health and wellness. Additional subthemes of storytelling, building relationships and overcoming isolation, and communication challenges were identified. With the social isolation that is inherit in chronic illness, the parent-child bond changes. The majority of patients reported stronger relationships with their parents. Researchers have reported similar findings of closeness secondary to concentrated time with them in the hospital (Lewis et al., 2013). Despite their losses, a subtheme of the value of altruism emerged. Each participant's responses indicated that they wanted to share what they had learned about health-promoting behaviors of physical activity with the next young adult cancer patient.

Childhood cancer survivors are clearly at risk for future health problems, and successful promotion of physical activity both during and after treatment could have significant health benefits. Zebrack et al. (2013) found that AYAs feel that counseling on incorporating exercise and nutrition is an important need that is currently unmet, especially while going through chemotherapy. Gilliam and Schwebel (2013) reviewed 14 articles predicting factors that either encourage or discourage physical activity across six domains in children and young adults. They developed an evidence-based conceptual model based on explaining the barriers to physical activity. Zebrack et al. (2013) found that reported barriers to exercise included feeling too tired, being too busy and a lack of equipment. van Dijk-Lokkart et al. (2015) designed a randomized controlled trial to evaluate the feasibility and effects of an intensive 12-week intervention program, combining physical exercise and psychosocial training. 174 patients were eligible for study inclusion and only 68 (39.1%) participated. Of the 106 patients who did not wish to participate, 61 (57.5%) completed a short additional questionnaire concerning their main reasons for non-participation. Parents reported the intervention to be 'too time consuming' (24.8%) and 'participation too demanding for the child' (12.8%), and the children reported 'too time consuming' (20.6%) and 'already frequently engaged in sports' intervention.

Our study validated the patient's perception of the loss of their former self. With medical team input lacking, they came up with their own solutions. Older patients identified their need for connection with others, including AYA patients, nurses, or friends. They felt they needed honest information about the negative consequences of inactivity. Their responses supported their need for individualized, attentive coaching for wellness behaviors.

The open-ended questions in the interviews revealed unmet supportive care needs. For example, the dancer can't dance, and the musician can't play or sing; these and other such talents could have been supported with interdisciplinary team interventions. This was particularly evident in our female patient who became valedictorian and spoke only Spanish when she was diagnosed. Every day she looked forward to the one-on-one contact she had with a Hispanic child life specialist. She felt this relationship with a person of the same culture not only helped her get through treatment, but it kept her focus on wellness and a connection to the outside world. Going forward, with increased awareness of unmet needs, we need to diligently plan patient care to try and meet the individual needs of our children and AYA patients.

The findings in this study are consistent with the previously published literature findings. A large majority of patients (26/30) described difficulty attending school secondary to diagnosis and medical treatment. A small portion of patients continued school and graduated with honors, or used the opportunity to develop mission statements and pursue college applications. The patients who described difficulties with school attendance linked this difficulty to physical weakness, lack of energy, or "chemo brain." They were grateful for teachers who stayed connected and encouraged their school engagement. Pini, Gardner, and Hugh-Jones (2013) completed a study with 88 teenagers. In their study, the teenagers were given a questionnaire about their education experience since their cancer diagnosis; the researchers found that connection to peer groups and body image promoted educational engagement and improved quality of life. To complement the patient data, 40 oncology providers also completed questionnaires, which inquired about the education experiences of oncology patients. They reported that peer relationships strongly correlated with educational success and engagement (Pini et al., 2013). Our research using candid, open interviews revealed that education goals can be disrupted and collaboration between peers, schools, and families is crucial.

The open-ended interview questions allowed the investigators to gain insight about what patients had been doing to remember their cancer journey and tell their personal story. Storytelling was used in a wide variety of both traditional and innovative ways. Most patients' used photographs to organize and tell their stories in a scrapbook, tablet, or computer. Some patients used memory boxes to store important reminders of their cancer treatment, including central venous catheters, hair, and Beads of Courage®necklaces. Patients' used a variety of methods to self-engage in story telling such as shared their story for a college essay or at a public event, or Beads of Courage® to record their narrative cancer journey. The young adults took their beads to school to show their teacher and classroom what they had been through. Some beads were more important to patients. One young woman remembers the special bead she received for hair loss, as this was a traumatic loss for her. These special beads seemed to "soften the blow" of this harsh memory and serve as a reminder of her resilience and strength. Another group reported on young adults using beads as prompts to tell their "beads of life" cancer narratives (Portnoy et al., 2016). Importantly, not all patients in this study wanted to remember their experience. Some patients did not keep any reminders of their experience. The diversity of mechanisms a patient chooses to utilize to remember, or to not remember, their cancer journey supports the need for a variety of innovative and creative outlets. Further efforts should continue to utilize nursing, child life specialists, art and music therapy, and mechanisms to keep patients connected to friends and family.

There are aspects of this study that may limit more widespread applicability of the findings. These findings may not accurately generalize to other adolescents and young adults with cancer due to a small sample ($n = 30$). Another limitation to this study was the inclusion of only English and Spanish-speaking patients. Patients from other cultures and ethnicities may have different perspectives on the cancer journey that are not captured in this study; further investigation into other cultures is warranted. The specificity of leukemia diagnoses was not completely captured as either AML or ALL, each of which have very different treatment protocols and impact on patient quality of life. Patients with different types of leukemia may have a different experience with their treatment and may have differing needs, particularly with school experience, connection to friends, and physical activity. Future studies should investigate this further.

Implications for research and practice

This study contributes to the body of knowledge regarding how children and AYAs with cancer and their families cope with their illness. More research is needed to validate the themes reported in the study. The methods by which we obtain information from patients are important. Open-ended questions provide an opportunity for insightful and honest communication. Evidence–based interventions for nursing staff caring for children and AYAs with cancer should be developed, tested, and implemented.

From a clinical standpoint, these findings underscore the need for healthcare providers to discover the patient's cancer experience. Physical activity programs should be developed, with an emphasis on socialization for children and AYAs, both inpatient and outpatient. Further efforts should be made to maintain school connection and completion and identify those patients at risk of dropout. New programs and interventions should be developed and studied to make the most of the patient's cancer experience, prevent loss of function and social connectivity, and study the variety of mechanisms by which they process their cancer narrative. Nurses and healthcare providers can facilitate helping patients' tell their stories through scrapbooks, social media, memory boxes, beads, or etc. Patients should be encouraged to remain connected to the activities they are engaged in prior to diagnosis and stay connected to their family, friends, school and community to improve coping with their illness. Future studies should investigate school issues among cancer patients. Even with the onset of new technology at the bedside, patients still want personal interaction to inform them and communicate in a positive manner. Although young adults prefer to be on a pediatric unit, they understandably prefer to be talked to as an adult and involved in decision-making regarding their treatment.

Conclusion

This study reveals the powerful influence of nurses and the need to deliver sensitive care to children and AYA patients. Nurses are uniquely positioned to support patients to remain active and engaged to prevent deconditioning, encourage socialization, and promote wellness. The investigators hope that the information derived from this study will be instrumental in developing interventions that will help patients and families work through the trauma of the pediatric and AYA cancer diagnosis and treatment.

CRediT authorship contribution statement

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