



Special Issue on Health Care Transitions

Empowering Adolescents and Young Adults to Support, Lead, and Thrive: Development and Validation of an AYA Oncology Child Life Program



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ARTICLE INFO

Article history:

Received 16 December 2018

Revised 2 April 2019

Accepted 2 April 2019

Keywords:

Adolescents

AYA

Cancer

Efficacy

Sustainability

Young adults

Teens

ABSTRACT

Purpose: The majority of cancer treatment programs do not focus on the unique psychosocial support needs of adolescent and young adult (AYA) patients. Recognizing this disparity, a freestanding children's hospital utilized an interdisciplinary approach to bridge the gap and develop a comprehensive program to address issues specific to new diagnosis, treatment, and survivorship in AYA oncology patients.

Methods and interventions: A pediatric hospital formed a multidisciplinary team to educate, engage, and empower AYAs to participate in the development of a comprehensive program.

Results: The program enables peer-supported social networking and empowers patients to invest in their treatment and survivorship. The number of newly diagnosed adolescent patients accessing our program has increased 40% since the program began in 2015; attendees at AYA events increased from 99 in 2015 to 1312 in 2018, as has the number of AYA events per year. Following program implementation, our NRC Picker score of 89.3% ranks above the 90th percentile of all children's hospitals (benchmark 81.2%) on questions related to "involving teens in their care".

Conclusions: AYA Programs can provide age-specific spaces, empowerment events, and specific education curriculum that meet the unique needs of adolescents and young adults and may positively impact patient satisfaction.

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Background

Every year, an estimated 70,000 adolescent and young adults (AYAs) aged 15–39 years old are diagnosed with cancer (NCI, 2018). In this age group, malignant neoplasms remain the fourth leading cause of death and the leading cause of disease related death. Due to recent advances in research and access to new treatments, survival for invasive childhood cancers has improved markedly with 5-year survival now reported to be as high as 83% (Keegan et al., 2016). Programs that support the diagnosis, treatment, and long-term health of patients diagnosed with childhood cancer are thus becoming increasingly important. Over the last 30 years, it has become apparent that AYAs with cancer have not demonstrated the same improved survival that we have seen in younger children (Bleyer & Barr, 2009; Lewis, Seibel, Smith, & Stedman, 2014). Lower survival rates are likely the result of multiple, complex factors, including distinctive cancer biology, lack of

participation in clinical trials, and complex psychosocial needs of this population (Bleyer et al., 2008). There is increasing evidence that appropriate location of care and access to AYA oncology experts facilitates participation in clinical trials and enhanced survivorship contributing to more favorable outcomes (Fernandez & Barr, 2006). Beyond tumor biology and treatment location, AYAs have distinct treatment and survivorship challenges. A diagnosis of cancer causes a significant interruption in educational and occupational trajectories, often at critical junctures. Cancer diagnosis affects social development, including friendships, family dynamics, and romantic pursuits from dating to sexuality to future fertility (Hall et al., 2012). This results in significantly elevated levels of psychosocial distress and worse Health-Related Quality of Life (Smith et al., 2013). Fortunately, there is growing awareness that many of the existing cancer treatment models are not ideally suited to the complex needs of AYA patients, who require a more comprehensive, multidisciplinary approach.

As a result, AYA cancer programs must be created to address these unique needs throughout diagnosis, treatment, and survivorship. While a standardized AYA model has not been agreed upon, areas of programmatic focus most often include: access to clinical trial

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enrollment, discussing and preserving future fertility, and long-term survivor care with psychosocial support to address mental health, wellness, self-care, peer support, sexual health, education and career guidance, and transition to independence. Review of best practices suggests that AYA programs should be patient-centered, acknowledging each patient's level of autonomy and maturity, promoting normalcy, and empowering them to master typical developmental milestones (Morgan, Davies, Palmer, & Plaster, 2010). Additionally, a strong collaboration among a multidisciplinary team is essential to care for the complex clinical and psychosocial needs of this patient population. The team may include: oncologists specializing in AYA, radiotherapists, surgeons, nurses, rehabilitation specialists, psychologists, educators, fertility and sexual consultants, teachers, social workers, child life specialists, and spiritual care practitioners (Ferrari et al., 2016).

Local problem

The oncology team at a freestanding children's hospital in Southern California experienced the impact a cancer diagnosis has on the physical and psychological growth and development of newly diagnosed AYA patients. This subset of oncology patients reported feeling "out of place" and "isolated", both in the pediatric hospital and in their peer groups. Patients were prone to depression, developmental regression and demonstrated poor coping skills. This was reflected by a lack of motivation to leave their rooms, participate in physical fitness activities, and socialize with peers. Furthermore, it was noticed, the AYA patients wanted to be involved in their care and wanted age-specific education, throughout both treatment and survivorship. It was quickly recognized that this growing volume of AYA patients needed a specialized approach to meet their unique treatment and survivorship needs.

Interventions

Program goals

To address this gap, a multidisciplinary AYA workgroup formed, dedicated to learning how to best support these patients and families. The initial goal was to educate, engage, and empower the AYAs to develop a program to address issues specific to new diagnosis, treatment, and survivorship. Ultimately this has led to a comprehensive program with broader aims to improve access to clinical trials, preserve future fertility, facilitate peer mentoring, enhance long-term survivor care, and support the psychological and social needs of oncology patients 14–26 years¹ old.

One of the early initiatives and successes of the workgroup was to encourage peer interaction and promote physical well-being through the implementation of an inpatient fitness program called Rock the Halls. This innovative initiative was developed by bedside nurses with input from a physical therapist to encourage patients to walk the halls of the inpatient oncology unit and record each lap walked. There was a daily prize for the patient with most laps walked. This seemingly simple competition successfully motivated patients to increase their physical activity and socialize with others. Patients began walking their laps together which led to informal socializing in a dedicated teen room. Peer relationships organically developed as patients instantly connected through their shared experience of cancer and an ability to intrinsically relate they were missing in their peer groups. Rock the Halls quickly grew and the AYA workgroup partnered with the hospital Foundation to hire a dedicated AYA child life specialist to lead the development of a more comprehensive program. In September of 2014, the AYA child life specialist joined the team and collaborated

with the workgroup to evaluate existing resources and develop a strategic plan to advance the program. The following key areas of focus were identified: AYA leadership development, psychosocial support including peer socialization, peer mentoring, and cancer-related education and survivorship skills.

Leadership development

The AYA child life specialist established a patient leadership team to give AYA patients a voice in the growth and development of the program. The AYA patient leadership team is a group of patients and siblings with diverse diagnoses and experiences who are passionate about sharing their stories and eager to advocate for their peers. A major focus during the first two years of program development was investing in this core group and building their leadership skills, through national and international conferences, public speaking opportunities, and monthly leadership meetings. By exposing these patient leaders to oncology professionals and peers from across the world, they developed a clear sense of the needs of the AYA group and were able to guide the program to areas most needed to improve their knowledge and skills. These patients and siblings are the true leaders of this program and work closely with the AYA workgroup to give their input into all aspects of the program.

Psychosocial support

As this was a new and emerging field, the AYA child life specialist initially committed to learning about this unique group of patients. Using her background in child life, she started with focusing on developing rapport with the AYA patients, whether walking the halls with them, sitting at their bedside listening to their stories, or finding creative ways to motivate and engage them in their care. The success of Rock the Halls inspired the idea to coordinate weekly social events to continue to bring patients together to share their lived experience with cancer. Support and guidance from peers who are going through a similar situation fosters a personal connection that may improve coping skills, reduce isolation, enhance information sharing and a better understanding of the experience and future, and result in greater confidence in advocating for their care (Campbell, Phaneuf, & Deane, 2004). Weekly events consisted of game nights, movie nights, art and cooking classes, and fitness competitions. Increasingly patients were coming out of their rooms and engaging in these activities and socializing with their peers.

"Never had I ever felt comfortable enough to talk about cancer-related things with my friends from school. As close as they were, I didn't want to make anyone uncomfortable.... In AYA, I was able to talk about pretty much anything and everything because they understood. They had all been through it, and they were there to listen."

[-Male AYA patient, diagnosed with Non-Hodgkin's Lymphoma at 17 years old]

While successful, these events were solely aimed at the inpatient population and did not provide support to patients receiving outpatient treatment, nor did they engage survivors. To increase the support provided to the broader AYA oncology population, the program transitioned to hosting monthly events including off site activities such as bonfires, outdoor movies, and trips to sporting events. In addition to the planned activity of the evening, every event facilitates socialization and provides an opportunity for one patient to share their story. The most universally attended social event for our AYAs is our annual prom, which started seventeen years ago and has grown significantly since the creation of a dedicated AYA program. This special evening aims to make AYA cancer patients' dreams of attending their high school prom a reality. Though going to a traditional prom is not always possible for teens battling long-term, life-threatening illnesses,

¹ National Cancer Institute defines AYAs as 15–39 years of age. 14–26 years was selected as a site specific age range based on the patient population we care for.

this night ensures patients do not miss a chance to dress up, dance, and celebrate their journeys. This event is more than just a dance, but rather, represents all adolescent and young adult milestones that they have missed or may never see including: graduation, college life, quinceañeras, dating, weddings, and more. Knowing the importance of this milestone, the medical team even creates plans for the most critical patients to allow them to attend. Since the program creation, attendance at prom has nearly doubled with 300 people at our most recent event.

Peer mentoring

It is well documented that cancer patients often engage in altruism as a coping strategy (Di Giuseppe et al., 2018). Peer mentoring provides a meaningful way for patients to process their own emotions while supporting their desire to contribute to the greater oncology community. Across the first three years, our AYA leadership team has driven initiatives to give back to their peers, the younger patients, and their parents.

In this spirit of altruism, the patient leadership team began a Big Patient/Little Patient and Big Sib/Little Sib program to mentor younger patients and siblings through treatment.

“This program helped me be a better caregiver and stronger as a sister. Being part of this program changed my perspective in life, it gave me a hope for a better future, and eventually taught me to be a mentor to other patients and caregivers who also needed support through their treatments.”

[–Female, bereaved sibling of a brother with acute lymphoblastic leukemia, 24 years old]

The team organized a scavenger hunt for younger patients/siblings, a park cook-out to celebrate their siblings, and a night honoring their parents. An annual three-day mentor retreat has also been incorporated into the program to provide mentorship training and survivorship skills to AYA survivors who are interested in serving as mentors to their peers. The trained AYA patient and sibling mentors are paired with newly diagnosed patients to be a source of hope and act as a peer guide and friend to help them through the cancer journey. The AYA mentors are also tasked with greeting new patients that attend the AYA events and welcoming them into the AYA community.

Cancer-related education & survivorship skills

To provide real-time education on diagnosis, treatment, and procedures, the oncology healthcare team performs daily multidisciplinary rounding on all patients. The team (including the patient and family) collaborates to set patient specific goals for ambulation, nutrition, and medication compliance. Dedicated psychologists, child life specialists, and social workers collaborate with the nursing staff to develop rapport with patients and families and provide ongoing services including strategies to reduce fear and anxiety and increase coping. Representatives from each of these disciplines form the backbone of the AYA multidisciplinary team and work as advocates for these patients in the day-to-day routine of hospital care.

“The AYA group has become my second family that has guided me through tough times, embraced me when I cried, celebrated alongside my victories, and understands how I feel without speaking a single word.”

[–Female AYA patient, diagnosed with Hodgkin's Lymphoma at 19 years old]

Palliative care is incorporated into the plan of care, as appropriate, and *Five Wishes* (Wiener et al., 2008) or *Voicing My CHOICES™* (Wiener et al., 2012), as well as memory making activities, are proactively presented to allow the adolescent time to be involved in the decision making and to optimize their quality of life. This support empowers

the AYAs to gain control over their healthcare and become an active member of their care plan.

“Our AYA program gives me a source of hope, strength, and inspiration. Hope to come out of my journey victorious, strength to continue fighting, and inspiration to keep others positive throughout their journey.”

[–Male AYA patient, diagnosed with acute lymphoblastic leukemia at 17 years old]

In addition to the routine support and education, the patient leadership team requested a formal education series be developed based on topics that were chosen and prioritized by the patients (Fig. 1). Nurses and child life specialists then used this educational needs assessment to develop a comprehensive AYA specific education curriculum to address these needs. While many of these topics are discussed at diagnosis, patients wanted the opportunity to engage in ongoing discussion in a safe, comfortable, and dynamic learning environment. A variety of teaching styles were implemented to enhance learning and engage powerful and insightful discussion in both formal and informal settings. These approaches included dinner meetings, expert panel discussions, guest speakers, interactive group activities, weekend retreats, national/international conferences, and a career/resource fair.

We recently had an education night on fertility, the first topic in a series of education nights on matters pertinent to the oncology realm. We heard from a panel speaking about the biological effects of treatment and the ways the drugs affect fertility as well as from many speakers on non-traditional ways of starting a family. Their stories and smiles when talking about their children allowed me to realize that there are many different ways to start a family, and that biological relatedness is not a necessity for having a happy family.

[–Female AYA patient, diagnosed with Hodgkin's Lymphoma at 19 years old]

Results

Initial metrics to quantify the indirect benefits and assess overall efficacy of the AYA program have included: volume of AYA patients treated, number of patients participating in AYA events, and patient/family satisfaction survey data. The volume of AYA patients treated is derived from our cancer registry and patient/family satisfaction is gathered from the NRC Picker survey metrics. Satisfaction data specific to the AYA population were not collected prior to program implementation. Patient/family data from fiscal year 2016 forward were used to evaluate and benchmark against other children's hospitals. The total number of newly diagnosed adolescent patients, aged 14–26 years old, receiving treatment at the children's hospital increased 40% since the AYA Program began in 2015. The volume of AYA events increased from 6 to 33 per year; total number of attendees at AYA events increased from 99 in 2015 to 1312 in 2018 (Fig. 2). Additionally, patient/family satisfaction scores have sustained above the 90th percentile of all children's hospitals on questions related to the dimension “involving teens in their care” (Fig. 3). An unanticipated outcome of this program has been the tremendous sense of pride and ownership the patients and siblings have expressed in being involved in the creation and evolution of this program. In collaboration with the AYA workgroup team, the patient leadership team created the program mission statement “to empower AYAs to support, lead and thrive” and designed an original logo (Fig. 4). A music therapist worked with this group and empowered them to write and record an original song about their cancer journey (Fig. 5). This provided a creative outlet for AYAs to share their journey and express their emotions in a new and powerful way. In addition, the team collaborated with the hospital's marketing department to produce an AYA campaign to raise awareness and promote the program within our community. This included a video with patient and staff

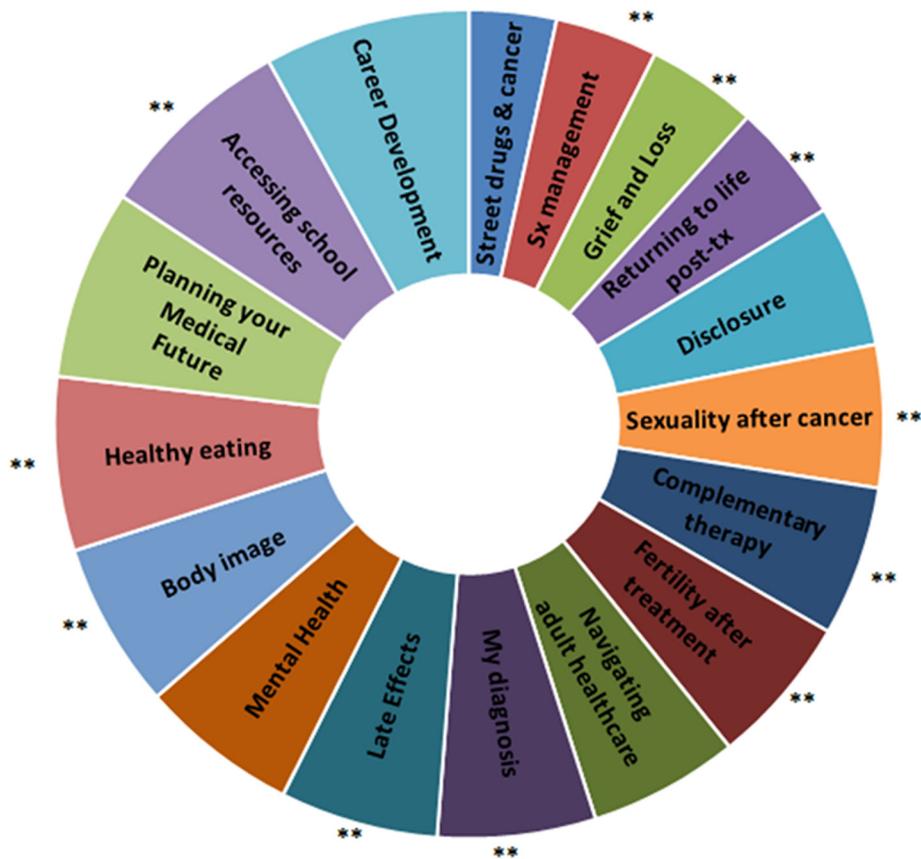


Fig. 1. Thirty-six AYA patients were surveyed to evaluate the needs of the patients. Topics around planning their future, mental health, and healthy living were the most significantly requested. ** = topics prioritized and covered.

testimonials (<https://www.choc.org/video/cancer-care-teens-young-adults/>). The video quickly went viral and is now housed on the organization's website to raise awareness of the program and to encourage new patients to become involved in the AYA community. The patient leadership team expanded on this to create a patient-run social media presence to encourage, educate, share events, and celebrate patient victories and milestones.

The following narrative from an AYA program participant validates the importance and meaning of the program and inspires team commitment to ongoing programmatic growth:

"I was diagnosed with stage IV Hodgkin's lymphoma... I was hesitant to join (the AYA activities) for months in fear of befriending someone and later receiving bad news, but after repeatedly hearing about the group, I decided to check it out. I attended the...AYA event—a painting class, where I met the AYAs for the first time. After talking with everyone, I immediately fell in love with them and the dynamics of the group as a whole. Everyone was friendly and welcoming and I could relate to them instantaneously. It was nice to finally have someone to talk to about treatment that could truly understand the young adult patient perspective."

Monthly game nights are generally my favorite AYA events. These are held at the hospital, which allows for inpatients and outpatients to spend quality time with one another just chatting and playing games in a relaxing setting...One of the most memorable AYA events was the Oncology Prom where the hospital was transformed...and our AYA group transformed from wearing casual attire into wearing beautiful dresses and handsome suits. For everyone in our AYA group, cancer and the treatment has changed our appearance—whether that's a loss of hair, a change in weight, visible scars, or the removal of a limb so it really was amazing to see everyone dressed up, feeling confident, and having a great time!

...A lot of the support offered by the group has been in terms of survivorship—returning to school, navigating long-term side effects, feeling beautiful even with my short hair. Through my involvement in the group, sharing my story has become easier because at many of our AYA events, one person is selected to share their story and answer a few questions about their journey and after sharing with a smaller group, I have felt more comfortable speaking to larger audiences about my experiences.

The aspect of inevitable loss associated with a group of cancer patients is what originally made me reluctant to join. Loss will forever be difficult as it is so heartbreaking to lose a member of our AYA family. In times of grief and loss, we all come together to work through the pain of losing a fellow AYA as we keep their memory alive.

The AYA group has become my second family that has guided me through tough times, embraced me when I cried, celebrated alongside my victories, and understands how I feel without speaking a single word. There are so many diverse personalities in our AYA group and every one contributes in their own unique way. Although we've all heard the words, "you have cancer", and have shared similar experiences, each story is different and we are constantly learning from each other through our varied pasts. We use our experiences to help guide newer patients through treatment and work to grow our program through activities such as mentoring and hosting bone marrow drives. I truly could not imagine going through treatment or life now without the AYA family at my side!

[-Female AYA patient, diagnosed with Hodgkin's Lymphoma at 19 years old]

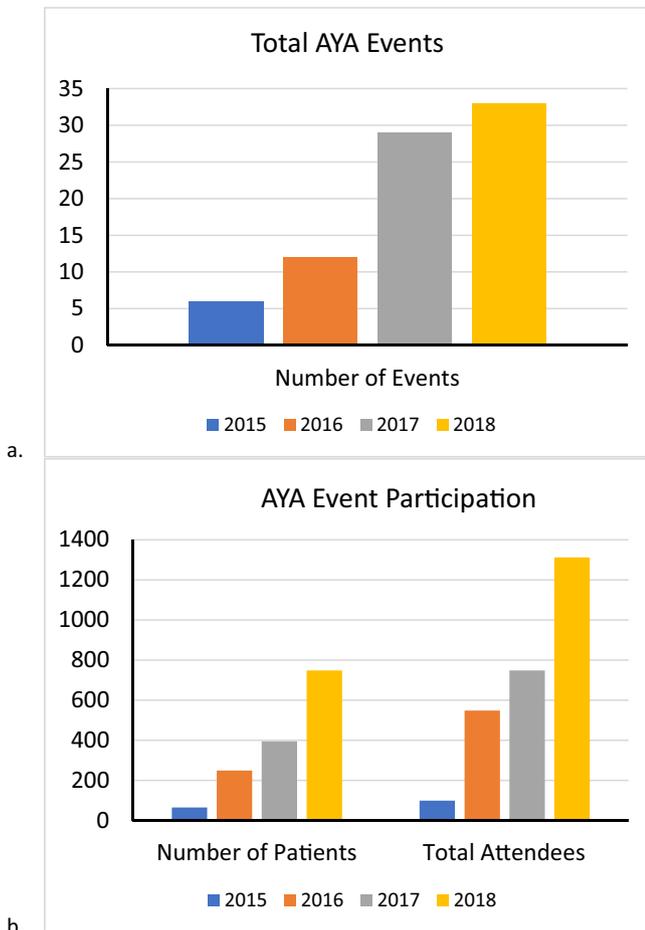


Fig. 2. AYA events and event participation.

Programmatic considerations

Summary

This comprehensive AYA Oncology Program consists of a patient-led, self-governed, multidisciplinary team guided by a dedicated child life AYA specialist in collaboration with a multidisciplinary team of nationally recognized AYA healthcare experts. The unique inpatient Rock the Halls fitness program has motivated AYA patients to stay active and decreased social isolation. Monthly empowerment events provide

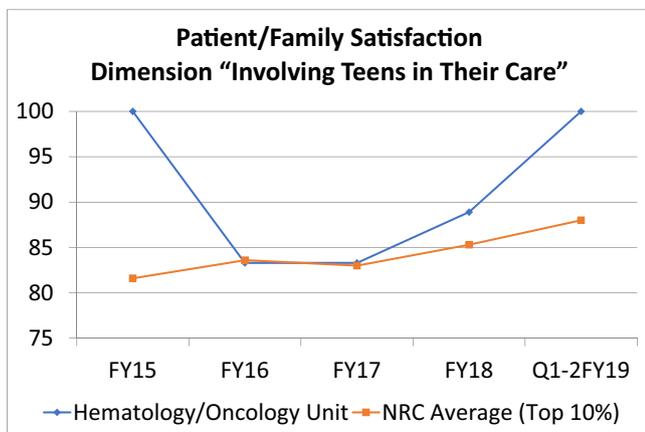


Fig. 3. Patient satisfaction scores.



Fig. 4. AYA Oncology Child Life Program logo.

peer support and socialization. The education series equips AYAs with the knowledge and skills to make informed decisions about treatment and survivorship, including participation in clinical trials and innovative

The Journey

It's been a long, long journey
 With little will left to fight
 Despite faring being rolled on a gurney
 We fought cancer with both courage and might

Chorus:

**All we need is a little hope
 We have our friends to help us cope
 They help us fight and be brave
 Even on our hardest days
 We'll continue to fight
 Despite all the long nights
 We don't care if our hearts are burning
 We are determined**

No matter our treatment length
 We all found our inner strength
 So together we must all fight
 To show our combined inner light

Chorus

Heroes are always remembered but legends never die
 You ain't gonna hear me say bye
 And you're never going to see me cry
 I'm like the sun rising up at dawn

Chorus x2

Fig. 5. Original song.

fertility preservation options. The annual 3-day mentor retreat strengthens leadership skills, empowers them to mentor and guide their peers, and teaches self-care activities to manage stress and anxiety. Education to maximize academic and vocational functioning has assisted survivors who are reentering the workforce and integrating back into the community. The AYAs in our community continue to engage in the program, both to build lasting relationships with peers and to foster their own growth and education, helping them to feel understood and to meet major developmental milestones.

Through education, peer relationships, and AYA events, the AYA Oncology Child Life Program supports patients and families through the challenges of treatment, empowering AYA cancer patients and survivors to take ownership of their treatment and invest in their survivorship. Each interaction is focused on helping AYA patients master crucial developmental tasks including establishing autonomy from parents, developing a personal set of values and identity, forming strong peer relationships, including intimate and sexual relationships, and successfully transitioning back to school or work and adult care (D'agostino, Penney, & Zebrack, 2011).

Future direction

Given the strength and diversity of the current program, the multidisciplinary team is working to identify and follow additional metrics, including patient outcome data to evaluate program efficacy. We strive to continue our strong psychosocial and educational programing, while grooming a new generation of leaders within the program. Next steps include the expansion of the oncofertility program to facilitate individualized counseling and follow-up and increased access to and availability of AYA-specific clinical trials. To improve nurse comfort in caring for this population, efforts are underway to implement comprehensive staff education on AYA cancer-related education topics. Finally, we will continue to build community partnerships with the adult medical oncologists to improve the transition to adult care and expand our reach to AYAs in the region.

Implications for practice

Development of a successful AYA program is dependent on the level of commitment of a diverse team, the availability of philanthropic support, and the engagement and empowerment of the AYAs themselves. Including the AYAs as a part of this team from the beginning sets the tone for the program and allows the adolescents to direct the focus of the program to their unique needs. Using patient volumes, patient satisfaction scores, and attendance at AYA events as surrogate short-term metrics of efficacy, our experience has demonstrated that an AYA program is desired by the AYA patients and empowers them to be involved in their diagnosis, treatment, and survivorship. Through patient stories, it is uniquely clear that an AYA program is effective in empowering patients and families to support, lead and thrive.

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Sharon Bergeron: Writing - review & editing, Supervision. **Kara Noskoff:** Conceptualization, Project administration, Writing - review & editing, Supervision. **Jennifer Hayakawa:** Writing - original draft, Writing - review & editing, Supervision. **Jamie Frediani:** Writing - review & editing, Supervision.

Acknowledgments

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This program is generously supported by Richard C. and Virginia A. Hunsaker and the Hyundai Cancer Institute at CHOC Children's.

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