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“You’re too young for this”: Adolescent and Young Adults’ Perspectives on Cancer Survivorship

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Adolescent and young adult cancer survivors face unique challenges not systematically addressed by cancer clinicians. Four focus groups and two individual interviews were conducted with 19 survivors to profile experiences and identify key concerns for future interventions. The resultant themes reflect cancer care continuum

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challenges (such as delays in diagnosis, problems with adherence), psychosocial concerns (such as infertility and reproductive concerns, changing social relationships, financial burden), and the paradox of being diagnosed with cancer as a young adult. Future intervention development for adolescent and young adult survivors should involve patient voices at each stage of the research process.

KEYWORDS adolescent and young adult, qualitative research, focus groups, cancer survivorship

INTRODUCTION

Adolescents and young adult (AYA) cancer survivors have been a historically understudied research population. Work conducted by the National Cancer Institute (NCI) and Live**STRONG** has countered this trend by highlighting the experiences of individuals diagnosed with cancer between ages 15 and 39 (Adolescent and Young Adult Oncology Progress Review Group, 2006), a diverse range of life stages for whom illness can affect and disrupt developmental milestones. Likewise, cancer advocacy organizations continue to push for increased recognition and responsiveness to AYA-specific needs (Bleyer, 2007). Adolescent and young adult survivors face challenges similar to those of older and younger survivors, including late effects of cancer and treatments, anxiety about recurrence, and an increased psychosocial needs burden as well as difficulties in accessing psychosocial services (Institute of Medicine, 2006). However, AYAs also have unique survivorship experiences: shifts in educational and occupational trajectories, often at critical junctures; effects on dating, sexuality, and romantic partnerships that can have a lasting impact; possible damage to fertility; and constraints on social support networks (Adolescent and Young Adult Oncology Progress Review Group, 2006; Hall et al., 2011). Feelings of uncertainty that accompany recovery, along with the recognition of the frailty of life, may influence survivors in how they manage their lives after cancer (Zebrack & Zeltzer, 2001). The impact of having to face this uncertainty for a long time and over several transitional life stages on AYAs, however, is not well understood.

Adolescent and young adult survivors are an understudied population, and little is known about their unique psychosocial needs. Using qualitative methods to illuminate survivor viewpoints in research legitimizes a role for local knowledge from survivors alongside that of health researchers and clinicians and allows a forum for a truly patient-centered understanding of AYA needs. Surveys alone cannot accomplish this simply because they predetermine which issues are likely to be relevant and include only these issues (Muntaner & Gomez, 2003). By providing a space to listen to AYA survivors, and in particular to the interactions among them, researchers can gain insight

into the mechanisms of AYAs' experiences and the directions that future investigations should take (Morgan, 1997). This study sought to profile the experiences of a selection of young adults living with cancer to better understand the issues that are most salient to these cancer survivors. Although existing research has accomplished the task of identifying and quantifying the needs of the AYA survivorship population (Kazak et al., 2010; Zebrack, Hamilton, & Smith, 2009; Zebrack, Yi, Petersen, & Ganz, 2008), this article uses qualitative methods to explore AYAs' priorities, and perspectives on the ways their unique situations affect psychosocial adjustment and interactions with the health care system. As such, this article deepens the extant knowledge base regarding the processes and factors distinguishing the AYA experience, and in doing so, provides conceptual and concrete guidance for health services delivery in this population.

METHOD

Focus group methodology was selected to elicit diverse perspectives through the process of engaging individuals who have shared a common interest (Morgan, 1997). In contrast with individual interviews, focus groups allow the facilitation of dialogue between multiple survivors, which provides an opportunity for participants to recognize the commonalities of their experiences and potentially feel more comfortable sharing commonalities. Focus groups also make it possible for participants to directly address other participants, and to drive the discussion, rather than just responding to and directing responses to the facilitator (Kieffer et al., 2005). We conducted four focus groups with young adult cancer survivors and conducted two individual interviews with AYAs who could not join the groups due to scheduling constraints. The individual interview data were ultimately included with the group data in analyses as the emergent themes were complementary. Each of the focus groups consisted of three to six members, totaling 17 survivors. In addition, two survivors were interviewed individually, creating a total sample size of 19. Participants were between ages 16 and 40 at diagnosis, an age range that encompasses the NCI/Live**STRONG** AYA designation (15–39). One half of the participants were female. The majority of participants were non-Hispanic White ($n = 15$) but also included three Hispanic/Latino participants and one Asian American. All participants had been diagnosed with cancer between 6 months and 6 years ago.

The objective of the study was to inform researchers and practitioners about patterns of shared experience in AYA survivors from time of diagnosis onward. Purposive sampling by age at diagnosis, cancer type, and gender was used to create diverse groups of young adult survivors (Bernard, 2002). Participants were recruited from the local Orange County, California, chapter of an AYA survivor network (I'm Too Young for This) as well as from patient

TABLE 1 Participant Information

Participant Alias	Age Range at Diagnosis ^a	Age Range at Interview ^a	Gender	Tumor Type	Treatment Phase
Adam	27–29	27–29	M	NHL	on treatment
Amy	15–19	20–23	F	Hodgkin's	survivorship
Carly	24–26	27–29	F	melanoma	survivorship
Chloe	24–26	27–29	F	NHL	survivorship
Chris	20–23	24–26	M	Wilm's tumor	survivorship
Dan	27–29	30–33	M	brain tumor	survivorship
Donald	24–26	30–33	M	testicular	survivorship
Elaine	15–19	15–19	F	ALL	on treatment
Evelyn	27–29	34–36	F	Ewing's sarcoma	on treatment
Hannah	24–26	30–33	F	AML	survivorship
James	20–23	24–26	M	NHL	survivorship
Jason	30–33	34–36	M	Hodgkin's	survivorship
John	20–23	24–26	M	aplastic anemia	survivorship
Maggie	27–29	30–33	F	ovarian	survivorship
Matt	34–36	37–39	M	multiple myeloma	survivorship
Olivia	20–23	30–33	F	NHL	survivorship
Rich	30–33	34–36	M	brain tumor	survivorship
Taryn	34–36	34–36	F	ovarian	survivorship
Tim	15–19	20–23	M	ALL	Survivorship

ALL = acute lymphoblastic leukemia; AML = acute myeloid leukemia; NHL = non-Hodgkin's lymphoma.

^aSpecific ages were restricted to protect participants' confidentiality.

records from the young adult cancer clinic at the University of California Irvine Medical Center. Depending on available contact information, potential participants were sent an e-mail, a letter, or telephoned about the study up to a total of 3 times. One individual and two of the groups were held in a college campus conference room, one group was conducted at a young adult cancer conference, and the remaining group met in the conference room of a local hospital where many of the participants had received treatment. One additional interview was held at a participant's home, and the other at the campus conference room. Table 1 provides demographic information about the study participants.

The format of all interviews was semistructured, framed around the following question: "What do scientists, doctors, and the general public *not* understand about adolescent and young adult cancer experiences?" Focus group methodology was employed to encourage interaction among participants. Probes were kept to a minimum and used primarily for clarification, as the emphasis was on letting each focus group shape the discussion that unfolded from the initial question. Each group lasted approximately 90 minutes and included either lunch or dinner. Informed consent was granted verbally, and the discussions were audio-recorded and transcribed.¹ The groups were facilitated by the primary author (and in one group, by the third author), and field notes were taken by three research assistants.

Text from the transcripts was categorized according to theorized and emergent themes (Glaser & Strauss, 1967). A form of narrative analysis, hermeneutic phenomenology, was used to identify and code themes based on the frequency with which they appeared in the texts, and more important, the level of importance the speakers placed on those themes. Hermeneutic phenomenology is an interpretive method that relies on the following elements: thick description of the encounters to be analyzed, critical reflection of the components and subcomponents of the text (words, then phrases, then passages) that relates each piece back to the whole, and a grounding of the phenomena under investigation within the context of the participants (Cohen, Kahn, & Steeves, 2000; Diekelmann & Ironside, 1998). The process of applying hermeneutic circles (a process of reading and rereading a text with careful attention each time to different portions of the text and how they relate) led to the identification of thematic universes² for further analysis (Freire, 2000). A grounded theory approach guided coding of analytical categories that emerged from the transcripts (Glaser & Strauss, 1967). Specifically, transcribed interview text was read and reread multiple times by the authors to understand the content of the interviews and to identify common themes. Initial emergent themes were identified and discussed according to the emphasis placed on these topics by study participants and by their recurrence within and across texts. Each participant's experiences were then reanalyzed within each thematic category to explore patterns of experience within a category. This approach led to the generation of the themes and subthemes reported in this article.

Data analysis was conducted and coding decisions were made by the two coauthors who facilitated the interviews. The rigor of the interpretations was further extended by ongoing discussion and feedback on findings from study team members, two of whom are affiliated with the survivorship advocacy community, and one of whom possesses substantial experience working in clinical practice with AYAs.

RESULTS

The adolescent and young adult participants discussed many of the issues that were salient to their cancer experiences. Most of the content of their discussions fell within the following thematic areas related to survivorship: (1) cancer care continuum challenges, (2) psychosocial concerns, and (3) the AYA paradox, a metatheme (or pattern) that emerged from the analytic process. Branching across the other two themes, this theme describes how the AYA experience is unique because of the disjuncture between the developmental expectations and experiences of young adults and the ways in which the cancer experience has been implicitly defined or understood

TABLE 2 Thematic Categories and Subcategories of Hermeneutic Analysis

1. Challenges in the cancer care continuum	Delays in diagnosis Problems with adherence
2. Psychosocial concerns	Changing social relationships Financial burden
3. The AYA paradox	Having cancer as an AYA

AYA = adolescent and young adult.

in terms of middle and later adulthood. Table 2 shows the categories and subcategories identified in analysis.

Challenges in the Cancer Care Continuum

The first theme represents participants' accounts of diagnosis, treatment, and follow-up care. Doctors, nurses, and other providers were praised for the quality of their care and compassion. At the same time, many survivors highlighted challenges communicating with their health care providers in two aspects of care in particular: in receiving timely diagnoses and navigating care processes.

Delays in diagnosis. Diagnostic delays have been cited as a major challenge facing AYA cancer patients (Martin et al., 2007) and were reflected in several participant comments. These comments illustrate a lack of awareness of potential signs and symptoms of cancer in AYAs on the part of patients and providers. One participant discussed not noticing changes in his health state:

I didn't have [any symptoms]. That's the scary part to me. That I didn't feel anything. I almost hope that my experience helps the people ... at least the people who were around me at the time, so if they see a little bump somewhere, they'll take initiative and, like, go [seek medical attention]. (James, diagnosed with non-Hodgkin's Lymphoma [NHL] in his early twenties)

Interactions with providers also seem to reflect incredulity at the possibility that a young adult could have cancer. This lack of awareness ultimately led to one survivor being diagnosed at a later stage:

Well, first of all, ... the doctors ... found a tumor on my ovary. And I said, 'Could it be cancer?' He said, 'No, you're too young for this.' (Maggie, diagnosed with ovarian cancer in her late twenties)

Failing to recognize early signs and symptoms of cancer can contribute to later stage at diagnosis and poorer prognosis. Once diagnosed,

participants continued to face challenges relating to their care, including difficulties communicating with clinicians.

Problems with adherence. Some participants related the challenges of understanding and adhering to complicated treatment regimens. One participant reported problems with medication adherence that included taking a higher dosage of steroids than intended. This individual referred to himself as an “idiot” for not knowing how to read the medication and warned:

Doctors, they shouldn't underestimate how stupid you can be about misreading the pill bottles and things. (Matt, diagnosed with multiple myeloma in his midthirties)

Misreading and misunderstanding medication instructions is a common phenomenon that has little to do with intelligence (Nielsen-Bohlman, Panzer, & Kindig, 2004), yet at least two participants blamed themselves for these errors. Health care providers may be less likely to assume AYAs would be prone to medication errors, but anyone, regardless of age, who is ill or lacks experience with health care system could make such errors. Another participant underscored this point:

I wasn't really well enough to pay attention to my medication and stuff. I had to do it all myself, but I didn't know about medicine and the doctors didn't really tell me enough details. And so, sometimes, I'd mess up with my medicine. One time, I was supposed to take these pills. And I took too many on accident. It was, like, sixteen pills on Monday. Once every two weeks. But I got it confused with sixteen pills every day. (Tim, diagnosed with acute lymphoblastic leukemia [ALL] in his midteens)

These comments illustrate the confusion that survivors can face in trying to comprehend and apply complicated medical instructions. They also support possible mechanisms driving lapses in adherence. Although AYA patients are often portrayed as noncompliant (Gesundheit, Greenberg, Or, & Koren, 2007), a portion of noncompliance may be involuntary, due to problems in provider communication and health literacy that are not limited to older adults, not to mention the stress of being ill that may further compromise capacity to fully comprehend and follow self-care instructions.

Problems relayed by participants with respect to communication and care coordination were consistent with problems already examined in the extant literature. These challenges included the depersonalization of care, a lack of empathy regarding the impact of diagnosis on one's life, and the lack of communication about late and long-term effects. Although not unique to this age population, it is important to note that AYAs experience these challenges too.

Psychosocial Concerns

Like older cancer survivors, AYAs face a wide array of psychosocial concerns as they transition into survivorship, including psychological and physical health effects, changing social relationships, and financial consequences of their cancer. In terms of psychological health, one difficult aspect of AYA survivorship reported by study participants was ongoing anxiety about recurrence. Survivors discussed anxiety related to surveillance and follow-up visits; one participant dubbed the associated emotional state “scanxiety.” Given that population improvements in survival are accompanied by higher risk for recurrence, AYA survivors may have to negotiate this uncertainty and the accompanying anxiety for years. Among the concerns raised were issues of infertility and having children.

Infertility and reproductive concerns. Although infertility was not a topic that was explicitly probed, it emerged in the interviews as an important issue. For those who discussed fertility concerns, many expressed remorse about the possibility of being unable to have children. One woman’s quote reveals the impact of discovering her infertility concurrently with her cancer diagnosis:

So that was, like, a double diagnosis right there: infertility and cancer on the same day. (Maggie)

Her designation of “infertility” and “cancer” as diagnoses reveals how she placed equal importance on both pieces of news. Another participant was told her chance of having children was limited and described how this information contributed to lingering stress. Despite her odds, this survivor became a mother of two after recovery.

Although most of the participants who discussed challenges regarding fertility were female, one male participant mentioned fears that he and his wife shared about being unable to have children. The rest of the male participants did not raise this issue. It is unclear whether infertility was not a concern for these participants, whether they had not thought about their own fertility, or whether they did not feel comfortable discussing these concerns. Survivors’ primary psychosocial concerns were related to changing social relationships and financial concerns related to survivorship.

Changing social relationships. Participants in the study reported that social support allowed them time to recuperate from their illness and treatment; likewise a lack of social support created stress and hindered healing. The benefits of having a partner, family member, or other trusted persons to aid with financial responsibilities, child care, transportation, and emotional support were directly tied to survivors’ quality of life and outlook on cancer itself. Nearly all participants emphasized the importance of having social support from a wide variety of sources, including caregivers and other

survivors in their broader communities. Some addressed feelings of being overprotected by their families. Others related stories of losing friendships or relationships as a result of their cancer experience. Although feelings of abandonment seem to be contradictory with feelings of being over-protected, many survivors reported the occurrence of social processes, often coming from different sources (for example, being over-protected by parents but abandoned by school friends).

Care received from parents, siblings, partners, and close friends was readily acknowledged by almost all participants. In this account, the cancer experience was described as creating a circle of supporters.

The friends and family that did find out have been so supportive. . . . It's been very medicinal and healing having all of the love and support from my friends and family. (Adam, diagnosed with NHL in his late twenties)

Absence of family close by or willing to help or lack of a romantic partner posed unique challenges for young adults. Survivors with dependents discussed the drive they experienced to keep pushing forward, even when they felt scared or tired or sick from treatment. They described this drive as a function of the need to take care of others:

Whenever I get chemo, I don't feel good and I have to be there for [my daughter] because she's dependent on me. So I have to keep on going. (Elaine, diagnosed with ALL in her midteens)

Elaine's comment reflects the intertwined experiences of fighting cancer and being a parent. These are two experiences that are deeply intense but also non-normative for an adolescent. Although her comment speaks to the role that dependents can play in helping to motivate AYAs, it also reveals how confusing it can be to become a cancer survivor and a mother at this age.

Some survivors expressed alternating appreciation and frustration for their family's role in their care. Survivors discussed grappling with their own emotional responses to the cancer experience, which were compounded by the need to also mitigate their caregivers' stress. The term *helicopter* (as in "helicopter parenting") was also used to signify family members' hovering and vigilance behaviors. These behaviors were described with positive and negative connotations; vigilance created a stable, supportive presence, but it also restricted privacy and independence. Some AYAs who had recently transitioned to living on their own found themselves living with their parents during and after cancer treatment. This presented benefits and challenges: the benefits of being cared for and supported and the challenges of feeling infantilized by their families and situations.

Another topic that emerged in changing social relationships was the importance of connecting with other survivors. Past research has suggested that connecting with other survivors is an important aspect of the healing process for young adults with cancer (Zebrack, Bleyer, Albritton, Medearis, & Tang, 2006). Many participants discussed how much they valued the relationships they had made with other survivors:

They called us “the three musketeers.” One of them was through everything, including the transplant. The next one, in the middle, she was . . . doing her chemo for her transplant. And I was the last one. . . . So I was the newbie on the block . . . [a]nd . . . there’s times of feeling alone and no one has any idea—from your mother to your boyfriend—has any idea of what you’re going through. So, I formed relationships and bonds with these two ladies and [we talked] all night long on the phone. (Hannah, diagnosed with acute myeloid leukemia [AML] in her midtwenties).

Although many survivors reported the value of finding a community of other survivors, some found it difficult to find survivors close in age and with similar interests:

When I was in treatment, the support groups that were available to me were men and women in their ‘50s and ‘60s. The men were all prostate cancer survivors and the majority of the women [had] breast cancers and here I am with my lymphoma as a 32-year-old, thinking I just want to get better because summer’s coming. I want to go to concerts and baseball games. (Jason, diagnosed with Hodgkin’s lymphoma in his early thirties)

Jason’s comment reflects the social isolation that AYA cancer survivors may face when attempting to establish peer groups or survivor networks that share common interests and face similar challenges. This issue is salient because it not only affects survivors’ social networks but may also affect their participation in research studies. For example, several participants indicated their participation in the current study was driven by an interest in meeting other survivors.

For many survivors, the experience of having cancer was catalytic in changing social relationships, either enhancing intimacy or creating distance. Some survivors who reported a loss of friends attributed this phenomenon to cancer and the discomfort it engendered in others:

Once you get diagnosed, you’re instantaneously probably going to lose about 90% of your friends because they get uncomfortable. It’s almost like we remind them of mortality and they don’t understand that just because, just because we have cancer doesn’t mean we’re going to die. (Dan, diagnosed with a brain tumor in his late twenties)

This phenomenon was not isolated to casual acquaintances; as one survivor noted, even close relationships could change and erode:

I actually lost my best friend through this whole thing. My best friend in the world . . . He just wasn't there for me. . . . And it was my best friend since we were 5 years old . . . he just wasn't there for me at all. And he didn't even call to see how I was doing. (James)

Two of the female participants reported getting divorced during treatment. Each expressed that the cancer experience catalyzed the breakups because their partners were not willing or able to support them through their disease. Many participants asserted that having cancer pushed them to be more direct and honest about the status of relationships and to be ready to end relationships that they could no longer prioritize.

Challenges related to initiating new romantic relationships and maintaining current relationships also surfaced. Most participants agreed that the experience of having cancer puts significant stress on new relationships. Most single participants either avoided the topic of dating, or mentioned they were not ready to begin dating. One of the participants reported difficulty believing he would be able to find someone to love him again, lacking the confidence and trust to begin dating. One aspect of the AYA experience that was not fully captured in the discussions was discussion of sexuality. Sexuality can be a difficult topic for cancer survivors to broach, regardless of age, and the focus group format of this study may have influenced survivors' discussion (or nondiscussion) of this sensitive topic.

Financial burden. Survivors described the challenges they faced related to securing and maintaining health insurance and supporting themselves and their families. Their comments reveal high levels of stress and worry and personalize the realities of being un- or underinsured as an AYA. Decreased survival for young adult cancer patients who lack health insurance at the time of diagnosis has been reported previously (Kent et al., 2010; Kent, Sender, Largent, & Anton-Culver, 2009), and the stories relayed in this study explain why: diagnostic delays, receipt of treatment in emergency rooms, and the concurrent stress of maintaining employment while undergoing treatment may exacerbate illness. Many young adults are independent and/or supporting young children and have difficulties suspending competing demands on their time and energy when undergoing treatment.

Approximately one third of the participants mentioned difficulties in acquiring or maintaining health insurance. Some lacked insurance before their diagnosis because they could not afford coverage and/or felt that they did not need coverage. Others had insurance at the time of diagnosis but worried about future insurability. It is common for young adults to begin their careers at jobs in which they are not offered health insurance coverage by their employers. Young adults may also experience a gap in coverage

between high school, college, and full-time employment. Survivors may find themselves unable to be covered by their parents but not in a position to obtain other insurance. Affordability and access to insurance was also a problem for participants who were working but did not receive coverage through their employers. This scenario can force AYAs to seek treatment in an emergency room, a nonoptimal strategy given crowding, wait times, and lack of continuity of care (Olson, 1994).

One day, a lump came out right here on my neck, as big as an egg. And then they did an X-ray and they found that all the lymph nodes on my spinal column and all over my body was really, really big. That it was a really growing . . . fast-growing cancer . . . I was going to the doctors. And I was paying cash. We didn't have insurance at that time. And when they found out from the labs that I had cancer, I went to the emergency room because I was almost dying. (Chloe, diagnosed with NHL in her midtwenties)

Chloe's account exemplifies the situation of being forced to visit an emergency room due to lack of insurance. Although the reasons for being uninsured varied, participants who lacked insurance at the time of diagnosis related stories of crisis. Lacking a health care home, a clear treatment plan, or strategy for paying for treatment compounded cancer-related stress. Participants who lacked insurance reported eventually being able to secure government-assisted insurance (usually Medicaid), but in all cases, they reported that this process delayed their treatment.

Young adults are often fulfilling and developing multiple new roles, given that early adulthood is often spent starting a career and raising a family. The perceived disregard by clinicians for the competing responsibilities that young adult cancer patients may have, such as taking care of young children, was evident in discussions. Although all cancer patients experience interruption in their daily activities, the concerns expressed by AYAs suggest a gap in support and services aimed at assisting with needs such as childcare, transportation, and elder care.

The AYA Paradox

The AYA survivors who participated in this study revealed insights into the paradox of having cancer (a set of diseases more prevalent in older age groups) while being young and the resulting tension between being ill and necessarily more dependent on others while in the process of transitioning to independence. In most cases, the cancer diagnosis interrupted developmentally normative life plans, and in some cases delayed or prevented the attainment of important milestones such as attending prom, studying abroad, going to graduate school, getting married, and having children. Revenson and

Pranikoff (2005) discussed the concept of “off-schedule” illness, in which survivors are diagnosed at younger ages often have few age peers to relate to and no time to prepare for disease onset, which then leads to difficulty in securing resources and coping. One participant summed up this interruption:

I think, no matter how old you are when you're diagnosed, there's always interesting circumstances that happen in that point in time, but particularly in high school, there's prom; there's getting your driver's license. There's all those different types of things that get postponed or colored because of your experience while you're sick. (Amy, diagnosed with Hodgkin's lymphoma in her midteens)

Participants themselves expressed a feeling of surprise about having to deal with cancer at this point in their lives. They felt it represented a more significant roadblock than it would for either an older or younger patient.

I think what a lot of people don't understand is that when you're diagnosed and going through this cancer, you are . . . you're not the same as everyone else in the room. You go to see the oncologist and everybody else looks different. They're all, typically, much older than you. . . . In my case, they were more sick than I was. They have different concerns. My wife would go to a support group and everybody there definitely had different concerns. She was interested in will she be able to have a baby and they're all interested in will they be alive. (Donald, diagnosed with testicular cancer in his midtwenties)

Some of the participants indirectly referred to symbols or metaphors that reflect the perceived exclusion of their age range in cancer care and research. One group joked about the magazine selection for patients receiving treatment in cancer centers, noting the selection included only children's magazines (e.g., *Highlights*) and magazines for older adults (e.g., *AARP* - The Association for the Advancement of Retired People). One survivor referred to the generational gap as a “diapers vs. dentures” issue. These comments reflect that not only is it difficult for AYAs to come to terms with their illness at their current life stage, they also struggle to find a place to belong in the health care system.

DISCUSSION

The young adults who participated in this study revealed deep insight about issues related to surviving cancer in adolescence and young adulthood. The themes that emerged from discussions with these young survivors reflect not only unmet needs but also a level of complexity should be recognized with interventions that are tailored to the needs of young adults. Results

support five key implications for future research in AYA survivors: improving survivor outreach across the cancer care continuum, addressing family and social relationships, increasing access and affordability of health insurance, providing career and educational counseling, and recognizing AYAs as a unique survivorship population.

Improving Communication Across the Cancer Care Continuum

Survivors' stories reveal opportunities for improving communication about cancer, treatment, side effects, and adherence to treatment and medication regimens. Past research has identified that AYA survivors need comprehensive information for treatment decision making, multidisciplinary provider teams, opportunities to connect with other young adult patients, and consistent and adequate health insurance coverage (Zebrack, 2008; Zebrack et al., 2006; Zebrack, Chesler, & Kaplan, 2009). The participants of this study suggest that a consistent and accessible system for organizing relevant health information is imperative, and that health care providers should consider how AYAs might prefer to receive this information. Current efforts to expand and standardize survivorship care planning (Institute of Medicine, 2006) should also consider the many life phases AYAs undergo as they transition through their cancer journey. Many may be highly mobile during this time period and may need a way to access their records remotely. Some may be transitioning off follow-up care at a pediatric center and may need to find a new medical home for their care. Care coordination over time, though critical for all cancer survivors, must be considered carefully for AYA survivors.

Addressing Family and Social Relationship Issues

The effects of cancer on relationships emerged as a dominant theme in the findings. The participants reported that in addition to providing care, family and friends serve other important roles in the coping and healing process, such as providing support and motivation. One study found significant discrepancies in the level of importance placed on connecting with peer survivors between patients and providers (Zebrack et al., 2006). Patients placed this as a top priority, whereas doctors and nurses ranked this significantly lower. The benefits of pairing newly diagnosed patients with other survivors or survivor networks have been increasingly recognized by oncology care providers, but awareness of opportunities to connect AYA patients to such outlets remain limited, as evidenced by the reports of several participants. Several support and advocacy organizations now provide services to help connect newly diagnosed patients with online networks. However, in-person peer support is limited, and avenues for creating such programs

should be further explored (Treadgold & Kuperberg, 2010). Furthermore, support services should be available along the cancer care continuum to help AYA survivors link to needed support to address their needs at diagnosis, during treatment, as they transition to recovery and years later as new developmental challenges history emerge (e.g., partnering and having children). Finally, information provision and counseling services for survivors and their support-givers to help with communication and managing relationships should be included in comprehensive survivorship care plans and integrated into follow-up care (Institute of Medicine, 2008).

Increased Access and Affordability of Health Insurance

Young adults in the United States are the least likely of all age groups to have adequate health insurance (Ward et al., 2008). Lack of health insurance can lead to delays in diagnosis (Martin et al., 2007), delays in receiving treatment (Burg et al., 2010), and decreased survival (Kent et al., 2009; Kent et al., 2010) in young adults with cancer. In addition to improving health care coverage for the general population in this age range, policies to provide insurance for young adults with cancer throughout their lifespan are necessary and long overdue. The United States Affordable Care Act of 2010 now allows individuals younger than age 26 to be covered by their parent's health insurance, prohibits lifetime limits, and phases out annual limits for coverage for essential benefits (Bleyer, 2010). These provisions have the potential to increase access to insurance and reduce some degree of financial burden, which could remedy delays in diagnosis and treatment for AYAs. However, AYAs may still experience difficulties as they age out of the coverage period. More comprehensive health care reform not tied to an arbitrary age limit and designed to promote preventive health care could shorten the time many individuals wait to seek medical attention, improve diagnostic and treatment delays, and reduce the financial burden and stress associated with being ill and uninsured.

Career and Educational Counseling

In addition to increased access to health insurance, AYAs need assistance with navigating career and educational trajectories and these concerns need to be integrated into comprehensive survivorship care. Survivors' reports about competing responsibilities while undergoing treatment underscore the need for health care providers to consider the many roles that young adult patients play and to remember that these may be new roles for young adults who are not well established in the workforce. Adolescent and young adult survivors in particular may need more assistance managing transportation

needs, child care, and reentry to school and to the workforce (Thompson, Palmer, & Dyson, 2009). Furthermore, guidance about employment protections for those with a disability or history of cancer should be routinely provided (Taskila & Lindbohm, 2007).

Recognizing AYAs as a Unique Survivorship Population

From diagnosis through treatment and follow-up, the results demonstrate instances in which AYAs felt the medical care system could have been more sensitive to AYAs' age and life stage. Some survivors suggested physician education programs in AYA medicine, to help train general practitioners and oncologists to recognize and respond to AYA issues. Challenges such as overcoming assumptions about AYA patient compliance (Gesundheit et al., 2007; Windebank & Spinetta, 2008), improving communication about treatment options (Zebrack, Chesler, et al., 2009) and fertility preservation (Fallat & Hutter, 2008; Hart, 2008), and maintaining better and more consistent long-term follow-up (Absolom et al., 2009) were highlighted in this study.

Limitations

This study has some limitations inherent to focus group methodology, including the restriction of only observing verbal behavior and self-reported data, in particular what is chosen and said aloud (Morgan, 1997). Participants are aware of being in a formal setting, of their distance from the facilitator, and of the presence of a recorder. In addition to the setting, the impact that the facilitator may have had on the discussion is not ignorable, although as the discussion progressed, participants tended to be more and more relaxed with their comments, indicating increasing comfort with the discussion. Although the number of participants was small, the sample yielded patterns that emerged with some consistency from the first to the last group and indicating that enough data were gathered to have gained complete accounts of the experience (referred to as "saturation"; Cohen et al., 2000). Furthermore, the use of thick description to highlight specific social context that the survivors in this study encountered as AYAs strengthens the likelihood that our findings are likely transferable to AYAs with other tumor diagnoses and from other regions (Lincoln & Guba, 1985).

Some AYA perspectives may have been omitted due to the composition of the sample. Although the sample includes individuals with a diverse range of diagnoses (representative of the most common cancer types in AYAs; Bleyer, Viny, & Barr, 2006) and is representative of both genders, it underrepresents individuals in the Asian Pacific and African American racial groups. Because of the sample composition, the experiences of these

individuals, as well as non-White AYAs more broadly, are underrepresented, as in most AYA research. This topic warrants future research, due to the unique ways in which disparities in detection, surveillance, and access to care during and after treatment may unfold for AYAs in underserved groups. Finally, study participants were recruited through an AYA survivor network and a comprehensive cancer center. All individuals were currently on treatment, actively engaged in follow-up care, or engaged in an AYA network. It is likely that those receiving care from a comprehensive cancer center were receiving relatively high-quality care and some degree of follow-up. Moreover, those who were involved in the AYA survivor network were familiar with AYAs as a “brand” and/or identity. The implication of these two intersecting factors is twofold. First, the study participants may be more aware and/or articulate about the needs and unique contributions of AYAs than the general population of AYA survivors. Second, this group may have had relatively better experiences with the health care system than individuals who are not actively engaged in treatment or follow-up care with a health care system. The implications of this are that we may have underestimated the overall impact of cancer on AYAs in many ways, such as financial burden, social isolation, and effects on education and career trajectories.

Future Directions

This study represents one of the few qualitative studies documenting cancer experiences in young adults (Jones et al., 2010; Miedema, Hamilton, & Easley, 2007; Peterson-Sweeney, 2005; Thompson et al., 2009; Yi & Zebrack, 2010; Zebrack, Chesler, et al., 2009). As such, it provides specific information about how and why AYAs’ experiences are similar to yet unique from other cancer survivors’ experiences. The accounts reported herein may aid future quantitative investigations by pinpointing key areas for exploration. Future inquiry regarding challenges faced by this population in seeking treatment should explore experiences leading up to diagnosis and should identify any barriers (self-imposed or external) that may postpone medical attention seeking. Inquiries into financial challenges faced by AYAs should include but not be limited to health insurance; rather, investigations should also seek to explore issues related to the competing responsibilities of maintaining employment and/or finding new employment during treatment and survivorship when one is at an early stage of career and job experience.

This study highlights specific unmet psychosocial needs that AYAs face along with insight into the paradox of being young and having cancer. Questions about how to best meet these needs remain, and as AYAs continue to grow in number, a long-range view on the dynamic needs of survivors is important for researchers and clinicians to maintain. We hope that studies using focus groups and other qualitative methods continue to provide a space

for survivor voices particularly as interventions continue to be developed and tailored for AYAs.

NOTES

1. Aliases were given to the participants for identifying their statements in this article.
2. "Thematic universe," a concept put forth by Paulo Freire (2000), refers to the "complex of generative themes" (p. 96) and involves meaning making that can only be born out of dialogical interactions among people. The term is used deliberately here to signify the interaction of multiple levels of themes that actually exist in the social world.

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