Effective Transitional Therapy for Adolescent and Young Adult Patients With Cancer: An Integrative Literature Review

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Effective Transitional Therapy for Adolescent and Young Adult Patients With Cancer: An Integrative Literature Review

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Background: The adolescent and young adult (AYA) cancer community has demonstrated a need for psychosocial help transitioning from acute cancer care to survivorship while navigating appropriate developmental challenges.

Objectives: The purpose of this integrative literature review is to examine the transition of AYAs from life as patients with cancer to life as cancer survivors and to evaluate the most effective, therapeutic ways to make this transition.

Methods: This integrative literature review focused on articles published from 2008–2015 using PubMed, CINAHL®, and PsycINFO. Key search terms were cancer, [adaptation, psychological], adolesc*, and young adult. Outcomes were evaluated using the Adaptation Model of Nursing.

Findings: Twenty-two studies met the inclusion criteria, but only four empirically examined interventions. Eighteen studies demonstrated AYAs’ unmet needs and suggested important therapeutic components. The four empirically examined interventions were dynamic group therapy, online cognitive-behavioral therapy, an online cancer forum, and an educational cancer retreat. Eighteen therapeutic themes were identified as integral to a complete and healthy transition. Five of these themes seemed to be of particular importance: education on cancer, coping, sexual identity, maintaining a sense of normalcy, and AYA support. The therapeutic themes demonstrate the highly individualized nature of transitional therapy and suggest that the type of therapy is less significant than the therapeutic components.

Adolescent and young adult (AYA) cancer is a new field that is growing rapidly yet still underdeveloped. Many authors have called attention to the knowledge deficit surrounding this age group, one of them highlighting the five-year survival rates for different age groups diagnosed with acute lymphoblastic leukemia (ALL) (Couzin, 2007). The five-year survival rate for children and adults has quadrupled since 1970, rising to 80%. However, the survival rate for AYAs is 50%, the same in 2007 as it was in 1970 (Couzin, 2007). Couzin (2007) attributes this stagnancy to lack of knowledge and research. This dearth of information may lead healthcare providers to treat AYA patients inappropriately for their age group, relying on evidence-based pharmacologic and nonpharmacologic treatment that has been successful in pediatric or older adult patients but is unproven in AYAs.

AYA patients are diagnosed with cancer at a socially crucial age. While they should be struggling with identity versus role confusion or intimacy versus isolation, per Erickson’s stages of development (Poole, 2013), they are instead facing their own mortality. One research study conducted a group counseling session for eight people diagnosed with cancer aged 22–29 years who were either in chemotherapy or remission (Thompson, Palmer, & Dyson, 2009). Among other frustrations, the AYAs discussed the difficulty of returning to normal life after no evidence of a
cancer diagnosis. Fern et al. (2013) conducted a workshop for AYAs aged 13–25 years who were diagnosed and treated for cancer within the past five years and noted, “Life after treatment was described as introducing more fear for which participants felt unsupported and unprepared. . . . Isolation during treatment continued on discharge as their friends had moved on, and participants’ outlook had changed” (p. E34). Patients may be unsure of how to transition and redefine “normal,” and healthcare teams may also be unaware of how to help them make this transition. Further research is necessary to discover not only how these individuals adjust back to life without cancer, but also how they progress in that life during a period of decades.

The purpose of this review is to examine the transition of AYAs from life as patients with cancer to life as cancer survivors and to determine the most effective, therapeutic way to help them make this transition. Evidence from research will be examined for its relevance to the AYA population and the implications for caring for this population during and after cancer treatment. The study will serve to provide education for all patients and healthcare professionals about emotionally healthy transitions and common obstacles throughout this process. Knowledge gained may help oncology nurses and other healthcare professionals provide better education for their AYA patients, helping them to more effectively transition.

Theoretical Framework

The theoretical framework that will be used throughout this study is the Adaptation Model of Nursing. According to the model, adaptation is “the process and outcome whereby thinking and feeling persons, as individuals or in groups, use conscious awareness and choice to create human and environmental integration” (Roy & Andrews, 1999, p. 54).

Adaptation leads to the greatest health and quality of life, as well as death with dignity. The patient’s level of adaptation corresponds to the state of his or her life processes. In the model, the levels of adaptation include integrated, compensatory, and compromised life processes. An integrated life process indicates a balanced, healthy lifestyle. When the integrated process is disturbed by a life event, it becomes a compensatory process that attempts to reestablish adaptation. If the compensatory process fails, the result is a compromised life process.

Roy and Andrews (1999) described four modes of adaptation: physiologic-physical, self-concept group identity, role function, and interdependence. The physiologic-physical mode refers to the physiologic processes and physical health of the body. Without optimal physical health, adequately adapting to the other modes is difficult. Self-concept group identity mode refers to psychological and spiritual strength, sense of self, and how the self reacts to others in the world. The role function mode considers the roles the person plays in society. Finally, interdependence mode focuses on how the individual relies on others for help (Masters, 2012).

The Adaptation Model of Nursing will be used to help determine the life process, or adaptation level, of AYAs as patients with cancer and cancer survivors. It will be integral to determining the success of AYA transitional therapy.

Defining Key Terms

The AYA population has yet to be consistently defined. As a result, each study focuses on a slightly different age range. For the purposes of this study, “adolescent” will be defined as ages 13–18 years, and “young adult” will be defined as ages 19–24 years, in alignment with the medical subject heading (MeSH) definitions of these terms (National Center for Biotechnology Information, n.d.-b, n.d.-c).

According to Erickson’s stages of development (Poole, 2013), adolescents experience identity versus role confusion, and young adults experience intimacy versus isolation. When an individual in this age group is diagnosed with cancer, it complicates their development; cancer may define an adolescent’s identity and role in society and may increase feelings of isolation in young adults. These complications do not diminish at the end of treatment. As one researcher demonstrated, many survivors express difficulty reintegrating into society after experiencing cancer during this crucial period of social development (Zebrack, Oeffinger, Hou, & Kaplan, 2006).

“Patient with cancer” refers to an individual diagnosed with a malignant neoplasm requiring treatment, such as surgery, chemotherapy, or radiation. Many studies have used the term “cancer survivor” to “describe an individual from diagnosis through the rest of their life” (Decker, 2007, p. 1). However, for the sake of clarity, “cancer survivor” will be used in this article to refer to an individual previously defined as a “patient with cancer” who has completed treatment, currently has no evidence of malignant neoplasms, and has successfully adapted according to the Adaptation Model of Nursing.

Methods

The researchers conducted a search of PubMed, CINAHL®, and PsycINFO with the following MeSH terms: cancer, [adapta*], psychological, adolescence, and young adult.

Articles were evaluated using the following criteria: (a) peer-reviewed research articles published from January 1, 2008, to June 1, 2015, (b) written in the English language, (c) AYA diagnosis of cancer for patients aged 13–24 years, and (d) articles referencing nonpharmacologic interventions post-cancer treatment. Some articles were also considered using ancestry, meaning that they were found as references in other articles included.

Medical, nursing, and psychiatric disciplines were considered. The search yielded 327 articles (258 from PubMed, 75 from CINAHL, and 25 from PsycINFO; 31 overlapped in the databases). Abstracts of these 327 articles were examined using the inclusion/exclusion criteria, and 29 were taken for further review. Twenty-two articles were eligible for inclusion.

Results

Of the 22 articles included in the review, only four presented empirically studied interventions (see Table 1). The remaining 18 articles, including quantitative, qualitative, and integrative literature review designs, focused on identifying AYAs’ unmet needs and presented suggestions for creating successful interventions.
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Empirically Studied Interventions

The four empirically studied interventions were group therapy, online cognitive-behavioral therapy (CBT), an online forum, and a cancer retreat. Baider and De-Nour (1989) conducted a dynamic group therapy with eight patients aged 15–25 years who had been diagnosed for more than 18 months. Four of the patients were in active treatment, and four were in remission. The group met weekly for three months, and each session lasted 1.5 hours. The emotional states of the patients were evaluated using the Brief Symptom Inventory (BSI), a self-report system that assesses patients’ psychological states, and the Global Severity Index (GSI), an indicator of a person’s degree of distress. Both were administered prior to and following therapy sessions. The BSI was given prior to the start of treatment and three months after treatment ended to the eight participants who had done group therapy. According to the study, the BSI scores did not change for any of the participants. The mean GSI scores increased for patients in active cancer treatment, indicating a higher level of distress, and decreased for patients in remission, indicating a lower level of distress. Baider and De-Nour

### TABLE 1. Literature Review Studies

<table>
<thead>
<tr>
<th>Study</th>
<th>Type, Sample, and Therapy</th>
<th>Design</th>
</tr>
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<tbody>
<tr>
<td>Baider &amp; De-Nour, 1989</td>
<td>Quantitative study with 16 participants aged 15–25 years using group (dynamic) therapy</td>
<td>Brief Symptom Inventory and Global Severity Index were administered at the start of the study and after three months. Eight participants refused therapy, and eight attended group therapy.</td>
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<tr>
<td>Canada et al., 2007</td>
<td>Quantitative study of 21 AYAs aged 15–25 years using individual counseling</td>
<td>21 AYAs were selected to participate in two individual 90-minute counseling sessions focusing on educational and supportive aspects of sexuality and cancer. All participants completed self-report questionnaires prior to the intervention, after the final session, and three months following the final session. Two groups were examined: one group undergoing the intervention immediately and one three-month waitlist control group.</td>
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<tr>
<td>Engvall et al., 2011</td>
<td>Qualitative study of 32 adolescents aged 13–19 years using coping strategies</td>
<td>Coping strategies examined included acceptance, distracting, fighting spirit, minimizing, seeking information, and seeking support. Data were collected via telephone interview four to eight weeks postdiagnosis, and at two, three, and four years postdiagnosis.</td>
</tr>
<tr>
<td>Ettinger &amp; Heiney, 1993</td>
<td>Qualitative study of AYAs using monthly support groups and weekend retreats</td>
<td>Self-report questionnaires and observation were used. The intervention focused on reinforcing health coping mechanisms for recently diagnosed patients with cancer, as well as patients long-term post-treatment.</td>
</tr>
<tr>
<td>Fern et al., 2013</td>
<td>Qualitative study of 11 AYAs aged 13–25 years</td>
<td>Four cancer survivors conducted interviews and activities with 11 AYAs, resulting in eight common themes, including coping, psychological support, and life after cancer.</td>
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<tr>
<td>Kumar &amp; Schapira, 2013</td>
<td>Qualitative study of 15 AYAs aged 18–30 years</td>
<td>Sample was collected by posting flyers; participants self-selected. Semistructured interviews were conducted individually that explored patients’ reactions to diagnosis, treatments, relationships, and reflections. Data were recorded and transcribed, then analyzed for common themes.</td>
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<tr>
<td>Love et al., 2012</td>
<td>Qualitative study with 350 randomly sampled posts from an AYA online forum from 2007–2010</td>
<td>Researchers identified “speech events” or “episodes of communication” and their primary communication goals. The events were organized by goal and examined by the researchers for frequency and common themes.</td>
</tr>
<tr>
<td>Sansom-Daly et al., 2012</td>
<td>Qualitative study of 90 AYAs aged 15–25 years using online CBT</td>
<td>This study was a background and setup for a trial study of Recapture Life–AYA, an online group-based CBT program for AYAs who completed treatment in the past one to six months. Participants were randomly sorted into Recapture Life–AYA, a peer-support group, or a six-week waitlist control group. Recapture Life–AYA and peer-support groups were offered in six weekly online sessions. Effectiveness was measured by surveys given at baseline, post-treatment, and after one year.</td>
</tr>
<tr>
<td>Zebrack et al., 2006</td>
<td>Qualitative study of 35 AYAs aged younger than 39 years using an educational retreat</td>
<td>35 AYA cancer survivors attended a four-day retreat at Camp Mak-A-Dream. A qualitative intake survey asked participants to identify three goals for the retreat, and an outcome survey allowed participants to evaluate the workshops of the program, what they enjoyed most, and suggestions for improvement.</td>
</tr>
<tr>
<td>Zebrack et al., 2010</td>
<td>Quantitative study of 17 AYAs aged 18–35 years</td>
<td>AYAs participated in one of two one-hour group interview sessions that focused on helpful and harmful practices in the duration of the cancer trajectory. The interviews were coded for common themes, which were then divided into four a priori categories.</td>
</tr>
</tbody>
</table>

AYA—adolescent and young adult; CBT—cognitive-behavioral therapy

Note. For Fern et al. (2013) and Zebrack et al. (2006, 2010), adaptation as patient was unknown or not applicable.

Note. For Baider and De-Nour (1989), Ettinger and Henley (1993), and Love et al. (2012), adaptation as survivor was compensatory. For Engvall et al. (2011), adaptation as survivor varied from compensatory to integrated. For Kumar and Schapira (2013), adaptation as survivor was compromised for group therapy and compensatory for group education and narrative telling. For the remaining studies, adaptation as survivor was unknown or not applicable.
(1989) concluded that group therapy for AYA patients with cancer can “decrease denial of certain cancer patients,” and recommended that psychotherapy be employed only when patients were in a “stable medical condition” (p. 37). They further recommended that the therapy should focus on the patient’s perception of the illness and adaptation to normal settings, as well as foster the individual’s ability to cope (Baider & De-Nour, 1989).

Sansom-Daly et al. (2012) presented a trial of online group-based CBT for AYAs aged 15–25 years who were recruited at treatment completion. The 90 participants were randomly sorted into one of three groups: the Recapture Life–AYA group, an online peer-support group (PSG), and a six-week waitlist control group. Recapture Life–AYA was an online CBT group that met for six weekly sessions with the same participants, psychologist, and homework assignments to be completed between sessions. The PSG was similar to Recapture Life–AYA, including six weekly sessions with the same participants and psychologist, but with less structured topics and no homework assignments. Sansom-Daly et al. (2012) suggested that Recapture Life–AYA may be an effective transitional therapy based on the popularity of PSGs that decreased AYAs’ sense of isolation. Based on previous studies, the authors mention “computer-based e-therapies” as offering enough convenience and anonymity that AYAs of all demographics may use them without the stigma of seeking help for mental health (Sansom-Daly et al., 2012, p. 2).

Love et al. (2012) conducted a qualitative study examining online forums and their significance for AYAs. The researchers examined text-only, deidentified files from one cancer support forum for “episodes of communication characterized by internal unity,” referred to as “speech events,” (Love et al., 2012, p. 556). The events were then categorized and quantified, and five supra-categories emerged: exchanging support, coping, describing experiences, enacting identity, and communicating membership. Ultimately, Love et al. (2012) determined that the uncontrolled online forum seemed to be a successful support and an asset for AYAs based on frequency, volume, and type of support provided and “how often members outwardly praised [the forum]” (Love et al., 2012, p. 558).

Finally, Zebrack et al. (2006) discussed the outcomes of a four-day educational and supportive retreat held for 35 AYAs aged 15–39 years who were diagnosed with cancer in childhood, adolescence, or adulthood. It should be noted that, although this age group extends outside the scope of this article’s definition of AYA, Zebrack et al. (2006) based their age group on a National Cancer Institute (2006) AYA Oncology Progress Review Group report. This review group identified major needs of the AYA community and provided five recommendations intended to serve as a blueprint to improving available oncolgic resources from screening to survivorship. The members of the group chose to define the AYA population as an “inclusive rather than exclusive” range, citing a lack of improving survival rates from 15–39 years (National Cancer Institute, 2006, p. 3). The retreat was evaluated with two questionnaires: one given before the retreat that asked the participants to identify personal goals and one at the end of the retreat that requested feedback regarding the workshops. The most commonly mentioned positive aspect of the retreat was the opportunity to meet other AYAs and create a community. The goals of the camp were to teach and encourage survivors to be advocates for other AYAs. Many survivors indicated that they felt prepared to return home and become further educated about their health risks and cancer, and create a sense of support for other AYAs. Zebrack et al. (2006) also mentioned the importance of the cancer narrative, or the ability of the survivors to share their cancer story. The researchers concluded that the retreat in itself was successful but suggested that future studies include post-retreat follow-up surveys to determine the long-term benefits (Zebrack et al., 2006). Success was measured based on how the goals of the retreat were met by the participants, detailed in their postretreat surveys. The ability to meet other cancer survivors and to share stories and experiences “can be enormously comforting and healing,” according to the researchers (Zebrack et al., 2006, p. 782).

Identified Interventions

Although not empirically studied, a few potential interventions were mentioned either in the articles’ discussions or as examples of interventions that AYAs sought post-treatment. These interventions were peer support from healthy friends and other AYAs, CBT, and individual counseling for psychological and other AYAs. The success of these interventions has not been determined.

Suggested Interventional Components

Eighteen important components of potentially successful interventions were identified in all 22 articles. These themes were identified by the authors as causing particular distress or help to AYAs, whether they are typical of all cancer experiences or exacerbated by the AYAs’ complex developmental state. Most of these themes are identified during cancer treatment and carried over into life post-treatment. These issues need to be addressed for AYAs to make healthy transitions to cancer survivorship. The 18 components each affect different modes of adaptation in the Adaptation Model of Nursing. The two components affecting physiologic adaptation are fertility and education on cancer. Nine components affect self-concept adaptation, which are internal and external coping; self-efficacy; issues of control; self-esteem; sexual identity; individuality; benefit finding; use of humor, venting, or optimism; and acceptance of cancer. The two components affecting role function were academic and vocational counseling and finding a sense of belonging. Finally, the six components affecting the interdependent mode of adaptation were maintaining a sense of normalcy, financial education, narrative development, family support, AYA support, and peer support. The most commonly referred to components will be discussed in this article.

transitions.

Coping: Nine articles identified coping as an important skill for healthy transitions (Baider & De-Nour, 1989; Engvall, Cernvall, Larsson, von Essen, & Mattsson, 2011; Ettinger & Heiney, 1993; Evan & Zeltzer, 2006; Kumar & Schapira, 2013; Sansom-Daly et al., 2012; Seitz, Besier, & Goldbeck, 2009; Tsangaris et al., 2014; Zebrack & Isaacson, 2012). When searched in MeSH, “coping” is redirected to “adaptation, psychological,” which is defined as “a state of harmony between internal needs and external demands and the processes used in achieving this condition” (National Center for Biotechnology Information, n.d.-a, para. 1). Evan and Zeltzer (2006) suggested that an important mechanism to understanding and facilitating AYAs' coping mechanisms throughout and after cancer is examination of their prediagnosis coping mechanisms. The same study mentions that promoting healthy coping skills at an early age may significantly affect the patient's ability to adapt after a cancer diagnosis (Evan & Zeltzer, 2006). Many interventions have been suggested to improve coping, including peer or group support and online forums and discussions (Sansom-Daly et al., 2012).

Individuality: Although individuality was only identified in two articles, it bears mentioning that therapy should be tailored to an individual's needs (Jacobsen, Bouchard, Emed, Lepage, & Cook, 2015; Tsangaris et al., 2014). The term AYA covers a wide age range and developmental spectrum. Effective therapy for a 17-year-old patient may be too immature for a 24-year-old patient and too mature for a 13-year-old patient. Jacobsen et al. (2015) discussed the concept of “being known” by healthcare providers, which was defined as developing a connection that identifies the patient as a human being distinct from his or her physical disease, including knowledge of individual personality and preferences. In addition, they described that AYAs may encounter an interesting issue regarding facility resources; the same 17-year-old may feel out of place in a pediatric facility and an adult facility. Therefore, therapy and treatment should be as individualized as possible to meet the greatest needs of AYAs (Tsangaris et al., 2014).

Sexual identity: Seven articles mentioned the AYAs' burgeoning sexual identity as a source of distress for patients, with two studies (Canada et al., 2007; Kelly, 2013) focusing specifically on psychosexual development and counseling (D’Agostino et al., 2011; Katz, 2015; Kumar & Schapira, 2013; Tsangaris et al., 2014; Zebrack et al., 2006). Establishing sexual identity and reproductive capacity are essential to the healthy development of AYAs (D’Agostino et al., 2011). Canada et al. (2007) cited a different article as suggesting that AYAs are at risk for long-term sexual impairment if the psychosexual issues associated with cancer are not addressed.

Implications for Practice

- Identify the specific psychosocial needs of adolescent and young adult (AYA) patients with cancer.
- Provide explicit needs of the AYA community for researchers to empirically evaluate.
- Prepare AYA patients with cancer for what to expect following cancer diagnosis and treatment to facilitate effective transitions.

The same researchers completed a study in which 21 AYAs aged 15–25 years participated in two 90-minute individual counseling sessions focused on sexual identity. Participant distress increased while waiting for the counseling session but decreased after treatment began (Canada et al., 2007). Canada et al. (2007) proposed that the most effective way to facilitate growth in sexual identity is through individual counseling sessions, which eliminate any potential discomfort of discussing these issues with other AYAs.

Maintaining normalcy: Maintaining normalcy was identified as one of the most crucial factors in AYA transitions and was mentioned in seven articles (Baider & De-Nour, 1989; Ettinger & Heiney, 1993; Katz, 2015; Kumar & Schapira, 2013; Tsangaris et al., 2014; Zebrack & Isaacson, 2012; Zebrack et al., 2006). Although adolescence and burgeoning adulthood can be isolating enough, AYAs with cancer may also experience a uniquely traumatic event. AYAs should allow cancer to become a part of life but not disrupt life. Katz (2015) discussed the concept of bridging the gap, guiding inpatient oncology nurses through the difficult task of creating a therapeutic environment for their AYA patients that allows for normal growth and development despite hospitalization. However, a delicate balance between maintaining normalcy and defining a new normal remains. Ramini, Brown, and Buckner (2008) noted that most AYAs reported the “desire to feel normal” (p. 75). Similarly, Zebrack and Isaacson (2012) discussed that AYAs appear to want to return to normalcy and proposed that an effective coping mechanism would be to continue schooling and stay in touch with peers. Kumar and Schapira (2013) identified the need for AYAs to individually determine what life after cancer looks like. The authors proposed that a self-help group with peers may provide the most adequate support for this group (Kumar & Schapira, 2013).

Adolescent and young adult support: Nine articles discussed the benefits of AYA support in transition to survivorship (Evan & Zeltzer, 2006; Kumar & Schapira, 2013; Love et al., 2012; Sansom-Daly et al., 2012; Tsangaris et al., 2014; Zebrack & Isaacson, 2012; Zebrack et al., 2006, 2009, 2010). Although family and peer support are important, many articles suggested that the most important support comes from peers who also have cancer. Love et al. (2012), Sansom-Daly et al. (2012), and Zebrack et al. (2006) presented interventions predicated on AYA support, and each suggested that the interventions, when implemented, were successful. AYA support not only diminishes isolation, but also improves...
Discussion

Although this study did not definitively answer the research questions, the interventions that were empirically studied and the identified important therapeutic components suggest that there is no “right” or “best” therapy for AYAs transitioning to cancer survivorship. Many of the distressing components identified by these authors suggest that the AYAs’ treatment experiences significantly affect their transition into cancer survivorship. Transitional therapy, therefore, should begin at diagnosis. Research examining the psychological benefits of such positive thinking may be indicated.

Therapy should be individualized and based on AYAs’ greatest perceived needs, likely among the 18 components identified in this study. The most frequently mentioned therapeutic components were education on cancer, coping, sexual identity, maintaining a sense of normalcy, and obtaining AYA support. These five components should be given special credence when considering AYAs’ developmental and psychosocial states and determining effective therapies for individual patients.

The adaptation mode from the Adaptation Model of Nursing most highly represented in the therapeutic components is self-concept, suggesting that therapeutic interventions should emphasize improvement in this mode for a better transition to survivorship for AYAs. Because the patient is already struggling with either of two stages in Erikson’s model (identity versus role confusion or intimacy versus isolation), the most effective therapies should focus first on the patient’s sense of self and then on that patient’s sense of self in the midst of others (Poole, 2013).

Limitations of this study include a lack of empirical research regarding effective transitional therapies and interventions for AYAs. Many studies have identified a number of unmet needs of this age group, but very few have conducted a scientific study of the outcome. Part of this dearth may be caused by low participation rates within the age group, making it difficult to carry out a scientifically significant study.

Conclusion

AYAs with cancer encounter a traumatic event during an already difficult developmental stage in life. After facing mortality and living, AYAs may struggle significantly with how to return to their lives and connect with their peers.

Adequate transitional therapy may take a number of forms but should begin at diagnosis and ultimately directly address the individual’s greatest perceived needs while providing support, education on the short- and long-term effects of cancer, healthy coping mechanisms, and maintaining a sense of normalcy. Future research should focus on empirical evidence of the effectiveness of specific interventions and their long-term outcomes.

References


