

Psychological, Social, and Behavioral Issues for Young Adults With Cancer*

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Theories of human development suggest that, although all cancer patients experience a common set of life disruptions, they experience them differently, focus on different issues, and attach different levels of importance to different aspects of the experience depending on the time in life at which they were diagnosed. During the critical developmental transition from childhood to adulthood, older adolescents and young adults in particular have typical concerns with establishing identity, developing a positive body image and sexual identity, separating from parents, increasing involvement with peers and dating, and beginning to make decisions about careers or employment, higher education, and/or family. Accordingly, cancer-related issues such as premature confrontation with mortality, changes in physical appearance, increased dependence on parents, disruptions in social life and school/employment because of treatment, loss of reproductive capacity, and health-related concerns about the future may be particularly distressing for adolescents and young adults. Psychosocial and behavioral interventions for young adult cancer patients and survivors often involve assisting these individuals in retaining or returning to function in significant social roles, such as spouse, parent, student, worker, or friend. Successful interventions will enable these young people to overcome the detrimental impact of a health crisis and strengthen the internal and external coping resources available to them. *Cancer* 2011;117(10 suppl):2289-94. © 2011 American Cancer Society.

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Few empirical studies of cancer patients and survivors have distinguished the unique psychosocial outcomes and service needs of adolescents and young adults. Although a sizable body of literature exists for young adult survivors of childhood cancer, the majority of psychosocial oncology research has involved samples of older adult patients or samples inclusive of adult patients across a wide range of ages. Haase and Phillips¹ suggested that there exists a gap in research, in that a common trend of clumping adolescents and young adults, roughly between the ages of 18 and 35 years old, with either pediatric or older adult populations has led to an inadequate understanding of the psychosocial impact of cancer for young people diagnosed in their late teens or young adult years. However, coupled with theories of human development across the lifespan,²⁻⁴ existing research suggests a unique set of psychosocial and developmental issues facing adolescents and young adults with cancer, and has stimulated recent development of support services and specialized care programs for this age-defined population group.⁵⁻¹³ This article serves as a general overview of some of the daily life challenges faced by adolescents and young adults with cancer. Its purpose is to increase awareness around the need for more age-appropriate psychosocial care and research. Critical reviews of emergent literature and more in-depth discussions are reported elsewhere.¹⁴⁻¹⁶

Adolescence and young adulthood are developmental stages marked by rapid changes in cognitive and emotional growth.² Thus, a life course perspective on cancer can advance our understanding of the unique ways in which cancer affects adolescents and young adults in particular. Theories of human development would suggest that, although all cancer patients experience a common set of life disruptions, they experience them differently, focus on different issues, and attach different levels of importance to different aspects of the experience depending on the time in life at which they were

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diagnosed. Rowland³ categorized a universal set of cancer-related disruptions that occur across all adult age groups/life stages and throughout a continuum of care that begins at diagnosis and continues through phases of treatment and eventual transitions to off-treatment survival or the end of life. These disruptions involve: 1) altered interpersonal relationships, 2) issues of dependence/independence, 3) achievement of life goals, 4) concerns about body-sexual image and integrity, and 5) existential issues. The experience of these disruptions varies according to an individual's age-related social roles (eg, parent, grandparent, spouse/partner, student, employee) and the life tasks and responsibilities associated with those roles. For example, the experience and meaning of intimacy, a significant factor affecting well-being, will be different for young, unmarried, or unpartnered survivors trying to figure out if and when to disclose the effects of cancer treatment to a potential partner, when compared with older adults in established relationships. Add in ways in which beliefs, attitudes, and values about religion, illness, medical treatment, and health care professionals contribute to behavior and experience, and the result is great variation both within and across cancer patients of various ages, racial/ethnic backgrounds or cultures, sexual orientations, and gender identities. Thus, given universal disruptions caused by cancer and their variation by age-graded life stages, psychosocial adjustment becomes the extent to which individuals are able to overcome the effects of these life disruptions in their day-to-day lives.

For many, a cancer diagnosis and treatment results in disruptions in daily activities, physical pain, diminished energy, changes to physical appearance, limitations in functional ability, altered social relations, confrontation with mortality and existential issues, and changes in one's sense of self, future, and world.³ However, individuals diagnosed with cancer during adolescence and young adulthood face additional challenges because of the intersection of the cancer experience with developmental tasks associated with this period.^{6,13,15,17} During the critical developmental transition from childhood to adulthood, young people have typical concerns with establishing identity, developing a positive body image and sexual identity, separating from parents, increasing involvement with peers and dating, and beginning to make decisions about careers or employment, higher education, and/or family.^{6,14} Accordingly, cancer-related issues such as premature confrontation with mortality, changes in physical appearance, increased dependence on parents, disruptions in social life and school/employment because of treat-

ment, loss of reproductive capacity, and health-related concerns about the future may be particularly distressing for adolescents and young adults.^{6,13,17,18} Investigations of the impact of cancer on quality of life and psychosocial outcomes must account for the developmental stage at which cancer disrupts these young people's lives.

Importance of Social, Peer, and Family Relationships

Identity development is a key aspect of healthy growth and development for adolescents and young adults. Successful achievement of this milestone requires healthy peer relationships, as identity development occurs within the context of social interaction.² However, isolation and alienation are commonly reported among adolescent and young adult patients and survivors, as they often miss out on experiences that their peers are enjoying, such as dating, leaving home and establishing independence, going to college, pursuing gainful employment, getting married, or having children.¹⁶ At the same time, a perception of high levels of social support can help teens and young adults with cancer cope with their illness and overcome the feeling that they are alone. Actively seeking support has been demonstrated to be associated with positive adjustment.¹⁹ Research identifies family support and cohesiveness as a most important contributor to positive adjustment²⁰ and family functioning as the single best predictor of distress, with poorer family functioning predictive of greater distress.²¹ Others identify the important role played by friends, including both healthy peers and other adolescent and young adult cancer survivors.^{22,23}

During this period of life, when individuals increasingly seek and experiment with intimate and sexual relationships, a diagnosis of cancer has the obvious potential to subvert normal adolescent and young adult development. Cancer and its treatment, as well as late or delayed effects associated with treatment (eg, early menopause, increased risk of osteoporosis, cognitive delays or defects, infertility, and chronic fatigue), also can affect developing sexual function, behaviors, attitudes, and identity in adolescents and young adults.²⁴⁻²⁹ Studies suggest that adolescent and young adult cancer survivors experience challenges or dissatisfaction related to sexual relations and intimacy.³⁰⁻³³ Altered perceptions of body image and self-esteem, changes in relationships, and other social life challenges can take a significant toll on adolescents and young adults, for whom exploring and developing sexual and intimate relations is the norm.^{28,34,35} Some adolescents and young adults adjust to the changes in their sexual

desire and function without distress. Others experience increased distress, depression, or anxiety, which then indirectly influences sexual function. Sexuality and intimacy are important components of a cancer survivor's quality of life, impacted by the diagnosis and consequent treatments. Unfortunately, many of these treatments and side effects are not as likely to resolve themselves in the short term, and some may be permanent, requiring adolescents and young adults to redefine a new normal for intimacy patterns, sexual behavior, parenting, and how he or she may define their sexual self.³⁶

A related issue for adolescents and young adults is the decision as to if, when, and how to share information about cancer with their friends and peers.³⁷ Another delicate issue is what and how much to say about their illness to new acquaintances, including employers. Faced with the potential for varied reactions, young people with cancer may lose confidence because of their uncertainty about whether and how they will be accepted. Opportunities for social interaction can help ease the stress of coping with the illness and renew young people's adaptive capacities. Furthermore, education and prompting regarding cancer survivors' rights in the workplace may increase the likelihood of them finding or retaining meaningful and gainful employment.

The most common concerns of cancer patients and survivors regarding disclosure appear to be when, how, and how much to tell a dating partner about their cancer history, as well as whether they will be rejected for revealing this information. Research suggests that cancer patients and survivors often experience negative feelings about their own attractiveness and sexuality, pessimism about their future relationship possibilities, uncertainty regarding disclosure of their cancer history to partners, and fears or actual experiences of rejection by partners.³⁸⁻⁴⁰ Some patients/survivors report feeling that their prior identity has been lost and replaced with a primary identity as a cancer patient.³⁹ Such feelings may result in difficulties in knowing how to talk with others without disclosing one's cancer. In contrast, some cancer survivors establish and maintain a positive identification with being a cancer survivor, in that they believe they are a better or stronger person for having overcome adversity.⁴¹ Some indicate that cancer has become a part of who they are, which often is shared with new friends and associates in early stages of new relationships. Unfortunately, this can also create problems for survivors when family members, friends, or acquaintances hold different understandings of the meaning of cancer and react negatively to this valued part of their identities.

Thus, opportunities for adolescents and young adults to retain or re-establish engagement with same-age peers will promote successful achievement of healthy identity development and well-being. Participation in teenage or young adult oncology camps, outdoor adventure programs, adolescent and young adult support groups, cancer survivor day picnics, and family retreats offer opportunities for life experiences that promote successful achievement of age-appropriate developmental tasks. For instance, an 8-day adventure trip for 17 young adult survivors of childhood cancer provided participants with an opportunity for physical challenges and resulted in reports of improvements in self-confidence, independence, and social contacts.³⁵ In addition, the evolution of Internet-based social networking sites like Facebook, the Lance Armstrong Foundation/LiveStrong's My Planet (<http://myplanet.planetcancer.org/>), and Stupid Cancer (<http://stupidcancer.com/>) are providing opportunities for young people to connect with others using technologies with which they are familiar.

In general, opportunities for peer involvement provide many adolescents and young adults with a chance to address areas of concern such as coping with uncertainty, dependency versus autonomy, social exclusion, separation processes, body image, intimacy, sexuality and fertility, and occupations with others whom they can observe as sharing similar experiences. Indeed, research suggests that opportunities to engage other adolescent and young adult cancer survivors improves psychological well-being⁴² and decreases psychological distress and anxiety about sexual and romantic relationships.⁴³ However, more research is still needed to demonstrate empirically who benefits from which types of supportive care resources and interventions, and at which points across the continuum of cancer care that is initiated at diagnosis and continues through phases of treatment and transitions to off-treatment survival or end of life.

Unique Psychosocial and Health Care Needs of Adolescents and Young Adults

Overall, a conclusion that can be drawn from the literature on adolescent and young adult cancer survivors is that most function well physically and psychologically,⁴⁴ although a subgroup experience clinically significant distress or mental health problems,⁴²⁻⁴⁴ and many continue to experience decrements in selected quality of life domains compared with peers who never had cancer.⁴⁵ For example, young adult survivors express concerns about their own health and physical appearance, and

about their future, including life goals, the health of their children, or the health and cancer risk to children they may have in the future.⁴⁶ They also continue to express concerns about finances, standard of living, job discrimination, and difficulties obtaining health insurance in the United States.⁴⁷

More so than those young adult survivors treated during early childhood, adolescents and young adults have greater cognitive capacities to understand the severity of their illness, and therefore may demonstrate persistent distress and anxiety over recurrence, death, or late effects.⁴⁸ Furthermore, studies inclusive of adult patients of all ages indicate significantly greater rates of distress among young adult cancer patients when compared with older adult patients.⁴⁹⁻⁵¹ Despite these problems, adolescents and young adults also may show considerable resilience.^{52,53} Young people who are able to accept and cope with cancer may gain a greater appreciation of life as a result of their illness experience, may mature faster than their peers, and perhaps are better equipped emotionally to handle the everyday challenges of life.^{54,55} Age-appropriate programs and services have the potential to minimize negative impacts as well as promote positive psychosocial adjustment; however, the availability of these services, although emerging, are still minimal, resulting in unmet needs for large proportions of the adolescent and young adult population.^{56,57}

Conclusions

Given the undesirable and untimely life disruptions experienced by adolescents and young adults with cancer, a critical task of the recovery process is to regain a sense of control over their lives as a means of attaining long-term adjustment and well-being. Psychosocial and behavioral interventions for adolescent and young adult cancer patients and survivors often involve assisting these individuals in retaining or returning to function in significant social roles, such as spouse, parent, student, worker, or friend. Successful interventions will enable these young people to overcome the detrimental impact of a health crisis and strengthen the internal and external coping resources available to them. However, despite the successes in medical treatment over the past 40 years, a full range of psychosocial services is not available to all patients diagnosed with and surviving cancer.⁵⁸ The work of the LIVESTRONG Young Adult Alliance exemplifies current advocacy efforts to raise awareness and influence health priorities in the United States regarding the specific health care needs of adolescents and young adults with cancer.⁵⁹ Research

efforts to identify and target at-risk subpopulations for culturally relevant and age-appropriate interventions are needed as well.

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