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# CHAPTER 1

## Introduction

What do we know about the psychosocial needs of young adults with cancer? And are they different from those of other cancer survivors? The answers are simply “a little” for the first question and “a lot” for the second. Young adults have traditionally fallen between the two worlds of pediatric and adult cancer. However, young adults are a unique population with developmental tasks and life experiences that are different from those in other life stages.

This book will describe what is known about the psychosocial needs of young adults with cancer, mostly from the perspective of descriptive studies. How to help young adults face and overcome the challenges of cancer at this stage of life will also be addressed. The audience for this book is members of the multidisciplinary team who provide medical, nursing, and psychosocial care for these young people. The goal is for these teams to provide the best possible care for young adult cancer survivors—care that is comprehensive, and evidence based and takes into account their unique needs and stage of life. This is the least of what they deserve.

### Emerging and Young Adulthood

Jeffrey Arnett (2011) is the foremost authority on the stage of life that he coined *emerging adulthood*—the ages between 18 and 24. The rationale behind this term is that over the past 50 years, the years between adolescence and young adulthood have taken on some unique characteristics that are not accurately reflected in adolescence (up to age 18) and young adulthood (age 25–45). Today, individuals engage in college education for extended periods, delay marriage and childbearing, and may live in their parents’ homes until their early 30s. Arnett (2011) noted that these years have key characteristics of

- Identity exploration

- Instability
- Self-focus
- Feeling “in-between”
- The age of possibilities.

It is in this stage of life that individuals explore their personal identities—whom they choose to love and what they choose to do for work. These judgments are based on their interests and preferences. This is a time of instability because inherent in the many choices is a change in partners, living arrangements, or educational direction. It is also a stage that is focused on the self because at this age, people have few responsibilities and obligations and are able to think only about what they want or need. At this stage, individuals feel as though they are in between adolescence and young adulthood. It is also the age of possibilities because of the hope and belief that they will become the adults they want to be.

Arnett (2012) described the 30s and early 40s (up to age 45) as *young adulthood*. He regarded the key characteristic of this stage as *role immersion*, in which marriage or a committed relationship and employment are cemented. It is in young adulthood that role demands are at their highest for most people, with commitments to a partner, children, and work.

It is within the roles and tasks of both emerging and young adulthood that cancer causes significant interruption. For ease of reading, the term *young adult* will be used to describe the individuals who are the focus of this book—those between the ages of 18 and 35.

## Concerns of Young Adults With Cancer

Cancer arrests the normal developmental processes of young adults by increasing their dependence on their parents, isolating them from their peers and exposing them to experiences that their peers cannot even imagine, and complicating the establishment of new relationships (Lewis, Jordens, Mooney-Somers, Smith, & Kerridge, 2013). Cancer creates physical burdens, affects future prospects, both in relationships and career opportunities, and brings individuals face to face with their own mortality (Kim & Gillham, 2013). Altered appearance and other body image issues, as well as potential loss of reproductive capacity, are major concerns for young adults with cancer (Zebrack, 2011). However, the cancer experience also has some positive effects, such as strengthened relationships with parents and peers, wisdom and insight beyond that which their peers have experienced at the same age (Lewis et al., 2013), and health competence and future goals (Bellizzi et al., 2012).

It is important to ask young adults what they want or need, as the opinions of their oncology care providers may not correspond with their own needs. For

example, in one study, young adults rated the importance of meeting other young cancer survivors higher than their healthcare providers thought they did. These relationships were more important to young adults with cancer than the support they received from their own families and friends (Zebrack, Bleyer, Albritton, Medearis, & Tang, 2006) despite what healthcare providers may think about support from existing relationships.

This study (Zebrack et al., 2006) determined the healthcare needs of young adults and ranked them by importance. Physical needs at the time of diagnosis and during treatment were

1. The presence of a multidisciplinary team that is knowledgeable about young adult needs
2. Treatment decisions that took into account risks to education, fertility, and other quality-of-life issues
3. State-of-the-art treatment protocols and clinical trials specific to young adults
4. Physicians who include cancer in the differential diagnosis when young adults present for care
5. Management of symptoms and side effects of treatment
6. Fertility-preservation services.

Physical needs during survivorship and off-treatment periods were

1. Ongoing surveillance of long-term effects of cancer treatment
2. Transition plans to primary care providers who will adhere to treatment plans
3. Recognition that off-treatment survivorship is a distinct phase of the cancer trajectory
4. Ongoing information for survivors about new treatments and long-term follow-up; tied with the need for evidence-based standards and guidelines for follow-up care.

Another study (Zebrack, Chesler, & Kaplan, 2010) identified the psychosocial needs of young adults in four areas: informational, practical, interpersonal/social, and emotional support. Of note in this study was the need for information that is delivered without condescension and patronization, preparation of the young adults for negative responses from peers and others, and the offer of love and affirmation from healthcare providers.

## **Quality of Life for Young Adults With Cancer**

Although this book does not focus on physical health, it would be remiss to ignore the impact of cancer on quality of life. The latest data from the Adolescent and Young Adult Health Outcomes and Patient Experience (AYA HOPE) study (Smith et al., 2013) show that young adults with cancer have poorer health-related quality of life than their healthy peers with defi-

cits in the areas of physical and emotional roles, physical and social functioning, and fatigue. As would be expected, quality of life is worse during active treatment, for those with current or recent symptoms, and for those without health insurance at any time since they were diagnosed. Those who did not have partners during their cancer experience had the worst mental health.

## What This Book Offers

The focus of this book is on the psychosocial needs of young adults with cancer from diagnosis through long-term survivorship and including end-of-life issues. Topics covered include psychosocial needs after diagnosis and during the treatment decision phase; the impact of cancer treatment on dating, relationships, and sexuality; and the potential for impact on fertility. For those who are pregnant at diagnosis, those who become pregnant after cancer, and those who are parenting, the impact of a life-threatening illness poses significant stress. Social relationships with peers, family, and colleagues at work or school also are explored. Recurrence is always possible, and this may mean that the young adult faces the end of life. Distress, an overarching emotion experienced by many, if not all, cancer survivors at some point in the cancer journey, is discussed in its own chapter, as are the supportive care needs of this population.

Although the amount of research in this population is increasing, there remains a paucity of evidence related to effective interventions for young adults with cancer. It is dangerous to assume that what works for older adults can be translated to young adults, especially those on the younger end of the age spectrum. Older adults have greater life experience, are often partnered, have adult children of their own, are facing retirement, and are closer to the end of their lives than the beginning.

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