

Introduction

In North America, more than 70,000 people between the ages of 15 and 39 hear the words “You have cancer” each year (Abramson Cancer Center of the University of Pennsylvania, 2012). Five-year survival rates now reach more than 80%, a significant improvement over the past 20 years (Bleyer, O’Leary, Barr, & Ries, 2006; Canadian Cancer Society Steering Committee, 2009), and more than one million people living now were diagnosed with cancer as young adults. That’s a lot of people and a lot of living. It is widely recognized within the oncology community that this group of survivors has needs that differ from those on either side of this age group (children and older adults). But what are those needs, and how are they being met? This book is a response to the question, What do young adults with cancer need to live full lives?

This book is divided into three parts:

- I. Being Sick
- II. Being a Person
- III. Being an Adult.

These divisions are not exact, and overlap exists among chapters and sections. Just like you cannot separate your brain from your heart and the rest of your body, you cannot sepa-

rate your life with cancer into discrete experiences. But every book needs some organization, and this is what I have tried to do with this book.

In the first section, **Being Sick**, you will read about treatment decision making, the emotional effects of living with cancer, survivorship care and surveillance, fertility and contraception, and living with metastatic disease and preparing for end-of-life care.

In section two, **Being a Person**, you will read about dating and sexuality; exercise, nutrition, and complementary therapies; and psychosocial support and dealing with family and friends.

The final section, **Being an Adult**, contains chapters on issues where you have to stand up and be counted: returning to work or school and participating in research and clinical trials.

Each chapter is based on the latest available evidence from a detailed review of the existing medical, nursing, and psychosocial literature. The goal is to provide you, the reader, with the best information to help you along your journey, either as a patient/survivor or as a family member, friend, spouse, lover, or healthcare provider.

In the appendix you will read the stories, much abbreviated, of the people who were interviewed for this book. There were 18 in total: 16 young adults and 2 mothers of young adults with cancer. You will read their words and learn about their experiences and feelings in textboxes interspersed throughout the book. While the statistics and studies tell part of the story, the words of those who have “been there, done that” are an integral part of what this book aims to do: to describe our essential understanding of cancer in young adults at this time and in this place.

What Is It Like to Have Cancer as a Young Adult?

Many studies have explored this question, and a group of researchers combined the results of 17 studies from 1987–2011 into one comprehensive model (Taylor, Pearce, Gibson, Fern, & Whelan, 2013). From their review, they described nine themes with supporting subthemes, which are presented in Table 1. Albeit coincidentally, the material in this book aligns with these themes and subthemes.

Needs—Met and Unmet

Another way of describing the experience of people with cancer is to explore their needs and to measure which were met, wholly or in part, and which were left unmet (which is not good). Researchers from Australia (Millar, Patterson, & Desille, 2010) did just that: they asked 63 young adults with cancer to respond to a list of 132 needs identified in previous studies. These young adults were asked to identify the 10 most unmet needs based on time since treatment (at or within one year; one to five years; and more than five years). Details of their unmet needs are presented in Tables 2, 3, and 4. What is shocking is the percentage of those who had multiple unmet needs in all three time periods. There is obviously much room for improvement in various aspects of care.

This is a long and frustrating list for those of us who work with young adults because we try our best to meet the needs of those we care for. However, to be living with unmet needs is another matter entirely. It is our fervent hope that this book will help to address, at least in part, many of these unmet needs. So read on—one chapter at a time, one section at a

time, as much or as little as you'd like. Feel free to email me (drannekatz@gmail.com) with your thoughts and experiences. Let me know if this book helped, even just a little, and how it could be better.

Table 1. Issues for Young Adults With Cancer	
Theme	Subthemes
Psychological function	Changes in appearance Coping General emotional impact
Importance of peers	Communication Friends without cancer Friends with cancer Death of a peer
Experience of health care	Place of care Relationship to professionals Provision of information
Importance of support	Family support Support from friends Support from health professionals General issues related to support
Impact of symptoms	Fatigue Symptoms in general Long-term impact
Striving for normality	—
Impact of diagnosis	—
Positive experiences	—
Financial consequences	Impact on employment State benefits

Note. Based on information from Taylor et al., 2013.

Table 2. Needs in Individuals Within One Year of Treatment	
Need	% Unmet
Leisure space and activities in hospital	61.9
Age-appropriate hospital care	57.1
Help dealing with boredom	47.6
Help finding meaning of experience	47.6
Access to better food in hospital	42.9
Guidance about future study or career	42.9
Feeling in control over life and decisions	38.1
Information about what happens after treatment	38.1
Complete and honest information about long-term impact of treatment	38.1
Help dealing with overprotective parent/carer	38.1

Note. Based on information from Millar et al., 2010.

Table 3. Needs in Individuals One to Five Years After Treatment	
Need	% Unmet
Help focusing on tasks and/or memory	36.4
Information about what happens after treatment	31.8
Help dealing with frustration	31.8
Information about feelings caused by cancer experience	31.8
Approachable healthcare providers	31.8
Help with unwanted thoughts, emotions, and images of cancer	27.3
Complete and honest information about having children	27.3
Help dealing with changes to who I am	27.3
Help dealing with overprotective parent/carer	27.3
Information about support services and available help	27.3

Note. Based on information from Millar et al., 2010.

Table 4. Needs in Individuals Five or More Years Since Treatment

Need	% Unmet
Help focusing on tasks and/or memory	40
To find enjoyment in my life	30
Help dealing with changes to who I am	30
Help coping with loss of independence	30
Help coping with being unable to do the same things as others my age	30
Help thinking about the future	30
Assistance in getting back to work	25
Guidance about future study or career	25
Help dealing with loneliness	25
Help dealing with the possibility of cancer recurrence	25

Note. Based on information from Millar et al., 2010.

References

- Abramson Cancer Center of the University of Pennsylvania. (2012, March 14). Did you know . . . the facts about young adults and cancer? Retrieved from <http://www.oncolink.org/coping/article1.cfm?id=1031>
- Bleyer, A., O'Leary, M., Barr, R., & Ries, L.A.G. (Eds.). (2006). *Cancer epidemiology in older adolescents and young adults 15 to 29 years of age, including SEER incidence and survival: 1975–2000* [NIH Pub. No. 06-5767]. Bethesda, MD: National Cancer Institute.
- Canadian Cancer Society Steering Committee. (2009). *Canadian cancer statistics 2009*. Toronto, Ontario, Canada: Canadian Cancer Society.
- Millar, B., Patterson, P., & Desille, N. (2010). Emerging adulthood and cancer: How unmet needs vary with time-since-treatment. *Palliative and Supportive Care, 8*, 151–158. doi:10.1017/S1478951509990903
- Taylor, R., Pearce, S., Gibson, F., Fern, L., & Whelan, J. (2013). Developing a conceptual model of teenage and young adult experiences of cancer through meta-synthesis. *International Journal of Nursing Studies, 50*, 832–846. doi:10.1016/j.ijnurstu.2012.09.011