

Chapter 9

Adolescent and Young Adult Concerns

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Since the publication of the National Cancer Institute Progress Review Group report, *Closing the Gap: Research and Care Imperatives for Adolescents and Young Adults with Cancer*, there has been an increasing effort to address the unique needs of patients between the ages of 15 and 39 diagnosed with cancer who often feel isolated between the worlds of pediatric and adult oncology. This group of individuals is now identified in clinical trials and in clinical care as the adolescent and young adult (AYA) population.

Historically, hematopoietic stem cell transplant (HSCT) has been applied selectively to younger, healthier patients, and hematologic malignancies are among the most common cancers of the AYA population. Therefore, attention to their age-specific needs constitutes quality care. Each domain of AYA cancer care (Table 9.1) should be approached with the patient's age and developmental status in mind. An ideal AYA team consists of medical providers, nurse specialists, social workers, vocational counselors, fertility experts, geneticists, physical and occupational therapists, and community-based services with peer support.

Priority concerns for these domains are listed below:

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Table 9.1 Domains of AYA cancer care

Domain	Examples
Medical	Oncology, palliation, nutrition, endocrinology, etc.
Emotional	Psychology, coping, distress
Physical	Exercise, activities of daily living, myopathy
Neurocognitive	Education, vocation
Social	Relationships with peers and providers
Reproductive	Fertility preservation, parenting options
Financial	Disability, insurance
Lifestyle issues	Environment, risky behaviors, balance with treatment
Late effects	Prevention, monitoring
Care community	Caregivers, family, friends

AYA adolescent and young adult

9.1 Medical

1. Leukemias, lymphomas, and germ cell tumors are common cancers among AYA-aged patients; HSCT may play an important role in the therapy of these malignancies:
 - a. Compared to children, the treatment-related morbidity and mortality may be increased for AYAs, but less so than for older adults.
 - b. Changes in initial treatment (such as pediatric-inspired therapies for acute lymphoblastic leukemia) have led to a reconsideration of the role of HSCT in first remission in some circumstances.
 - c. An increased understanding of unique biologic features in cancers among AYAs compared to children or older adults may alter prognostic tools and the recommended role and timing of HSCT for the AYA patient.
2. Attention to age-specific details related to growth and development may influence medical needs and care, including issues in endocrinology (see also Chap. 26) and nutrition:
 - a. Growth hormone
 - b. Thyroid
 - c. Gonadotropins
 - d. Adrenal
3. A variety of genetic syndromes may present with cancer in the AYA age range including Fanconi anemia, Li–Fraumeni syndrome, dyskeratosis congenita, and others.

9.2 Emotional

1. Distress, depression, anxiety
2. Issues of existentialism
3. Sexuality
4. Development of coping mechanisms

9.3 Physical

1. Changes in appearance
2. Sexual development and function
3. Activity limitations

9.4 Neurocognitive

1. Neuropsychological assessments
 - a. Consider formal assessment at baseline with follow-up assessments as indicated
2. Vocational training

9.5 Social

1. Changes in peer relationships
2. Family relationships (spouse, children, parents):
 - a. Loss of autonomy
 - b. Changes in roles and responsibilities
3. Coworkers and employer
4. Health-care providers, many of whom may also be young adults

9.6 Reproductive

1. Guidelines from the American Society of Clinical Oncology recommend that a discussion of the possibility of infertility be part of education and informed consent for all patients of reproductive age:

- a. Discussion should include risks, fertility preservation options, and appropriate referrals to reproductive specialists:
 - i. Every effort should be made to discuss fertility as early as possible after a cancer diagnosis
 - ii. Published guidelines also state that fertility preservation should be readdressed prior to HSCT.
 - iii. In addition to fertility preservation options, alternative parenting methods including adoption or surrogacy should also be discussed.

2. Males:

- a. Risk: Rates of azoospermia after high-dose conditioning regimens are as high as 90%, although rates for those treated with busulfan and cyclophosphamide are 50%, and with cyclophosphamide alone 10%
- b. Assessment: Semen analysis for quantitative analysis and motility
- c. Fertility preservation options:
 - i. Sperm banking:
 - Pros:
 - o Inexpensive
 - o Noninvasive
 - Cons:
 - o Hampered by findings of decreased sperm motility, azoospermia
 - o Psychological/emotional stress leading to inability to ejaculate
- d. Gonadal tissue cryopreservation:
 - i. This is the only method available for preserving fertility in prepubertal males and remains investigational.
 - ii. Theoretical risk of reseeding tumor cells after reimplantation of tissue

3. Females:

- a. Risk: Rates of ovarian failure after high-dose conditioning regimens are as high as 65–85%. However, this statistic may not be accurate as studies do not account for whether patients are trying to conceive. Younger age at HSCT may be associated with lower risks of infertility.
- b. Assessment: Follicle-stimulating hormone (FSH) and luteinizing hormone (LH), estradiol level, ovarian follicle assessment by ultrasound
- c. Fertility preservation options:
 - i. *In vitro* fertilization and embryo cryopreservation:
 - Pros:
 - o Well-established therapy
 - o Success rate of 26–36%

- Cons:
 - o Requires 2–3 weeks from initiation of therapy to oocyte retrieval
 - o Requires a partner for sperm donation or willingness to accept banked sperm
 - o High cost
- ii. Oocyte cryopreservation:
 - Pros:
 - o No fertilization required prior to cryopreservation
 - Cons:
 - o Oocytes more susceptible than embryos to damage during freezing/thawing
 - o Requires 2–3 weeks from initiation of therapy to oocyte retrieval
 - o High cost
- iii. Hormonal suppression with gonadotropin-releasing hormone (GnRH) analogue:
 - Pros:
 - o Easy to administer with no delay in therapy
 - Cons:
 - o Efficacy is not well established
 - o Not sufficient alone to preserve fertility in HSCT recipients
 - o Associated with bone loss which may cause other long-term complications
- iv. Ovarian tissue banking:
 - Pros:
 - o No hormonal stimulation required, therefore minimal risk of delay in therapy
 - Cons:
 - o Theoretical risk for reseeding tumor cells after reimplantation of tissue
- v. Gonadal tissue banking:
 - This is the only method available for preserving fertility in prepubertal girls and remains investigational.

9.7 Financial

1. Insurance (medical, life, disability)
2. Employment
3. Housing and transportation
4. Financial loss or bankruptcy

9.8 Lifestyle Issues

1. Substance use (alcohol, tobacco, recreational drugs)
2. Sleep patterns
3. Attention to flexibility in scheduling
4. Modifications to increase adherence

9.9 Late Effects

9.10 Care Community

1. Family (parents, spouse, siblings; see Chap. 34)
2. Partner
3. Peers (friends, AYA organizations)
4. Community (religious organizations, clubs, networks)

9.11 AYA-Specific Resources

1. National Cancer Institute (<http://www.cancer.gov/cancertopics/aya>)
2. NCCN guidelines (http://www.nccn.org/professionals/physician_gls/pdf/aya.pdf)
3. American Society of Clinic Oncology (<http://university.asco.org/focus-under-forty>)
4. Critical Mass: The Young Adult Cancer Alliance (<http://criticalmass.org>)

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