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PEDIATRIC ONCOLOGY (S EPELMAN, SECTION EDITOR)

The Adolescent and Young Adult With Cancer: State of the Art - Psychosocial Aspects

Claudia L. Epelman

Abstract Adolescents and young adults with cancer are a distinct subgroup of patients within oncology. From the onset of symptoms until the completion of therapy and beyond, they face physical, psychological, and social challenges that are significantly different from those of adults and children. Survival rates and quality of life outcomes for this population have not improved to the same extent that have for younger and older patients. Improvements in quality of care, overall survival and quality of life for these patients require access to specialized care and participation in clinical trials; assistance with management of disease and treatment effects (especially fertility and body image issues); assessment of psychosocial needs; facilitated transition to off-treatment care; and referral to age-appropriated information and support services. Staff team caring for young patients must be dedicated to working with this age group and should have specialist knowledge and training to support their specific needs.

Keywords Adolescent · Young Adult · Cancer · Psychosocial aspects · Quality of life · Optimal Care

Introduction

Adolescence and young adulthood are a unique and turbulent period of life of enormous physical, emotional, social and cognitive changes during which key developmental tasks must be achieved. These include the development of personal value systems and identity, independence from parents, taking responsibility for one's own behavior, and reaching financial and social autonomy [1]. Hormonal changes lead to alterations in physical appearance, changing body image, and sexual awakening. Cognitive skills develop with improved abstract thought and greater ability to understand consequences and make plans for the future. The need to socialize and to identify with peers intensifies. Alongside these changes, there is often an increase in risk-taking behavior as young people develop independence through testing limitations imposed by parents and authority figures [1].

During this transition phase, teenagers and young adults understand and define their functional roles with regard to lifestyles, careers, and relationships. They should learn who they are, who they identify with, and what direction they want their lives to take. It is a time for existential confrontation when young people need to reorganize their personality structure. The freedom to socialize independently, to choose a peer group, to test limitations, and to explore and define sexuality is an essential element in determining who an individual will become [2]. If teenagers and young adults complete their development successfully, they will emerge into adulthood with a positive self-esteem and body image, an established identity and emotional independence, and a realistic view of the future.

However, for those with a life-threatening disease, the complexity of achieving even some of these developmental tasks is immense. Acute illness or physical impairment is often followed by increased dependence on parents, requirement to conform to the values and beliefs of caregivers, and isolation from healthy peers [3]. Major changes in daily living must be faced as they endeavor to adjust to the shock of debilitating disease and treatment. Adolescent and young adult patients being treated for cancer feel isolated from their regular peers at school or work because of their illness [4]. Additionally, without maturity of abstract thought and development of cognitive skills that accompanies normal adolescence and young adulthood, they are less likely to achieve some of the abilities and responsibilities of their

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C. L. Epelman (✉)
Department of Pediatric Oncology, Santa Marcelina
Hospital / TUCCA, Rua Santa Marcelina 181 A,
São Paulo, Brazil
e-mail: clauepelman@uol.com.br

peers. Due to the disease and medical care demands or parental involvement, their opportunities and experiences are limited. Adolescents and young adults want to be treated as adults and feel that they should be able to cope with their fears and anxiety, but at the same time they long for the comfort and security of childhood. This inherent dichotomy intensifies their distress [5]. Moreover, young people with cancer have to come to terms with the fact that they have a serious disease for which the outcome is often uncertain. A diagnosis of cancer obviously doesn't fit adolescents and young adults' plans—making plans for the future in the face of a life-limiting condition may not seem worthwhile or possible.

Young people with cancer have specific needs that require specific care. Their still-developing emotional, social, spiritual, and cognitive status requires professionals to recognize the young person as an individual and assess their individual needs. Recognition of the needs of this age group is fundamental to their future development and subsequently to their quality of life [4, 6]. The multidisciplinary team should identify problems which are specific to these patients and care for them in the context of their unique world promoting the re- establishment of positive expectations about the future.

The Adolescent and Young Adult With Cancer

A diagnosis of cancer is likely to have devastating effects whenever it occurs, but is particularly damaging during adolescence and young adulthood. These patients have special needs that are not only unique to their age group but also more intense than those at any other time in life [7]. The complex nature of the disease coupled with young people developmental tasks, challenge coping strategies and exacerbate the natural ambivalence between childhood and adulthood [8]. The treatment demands contribute to lack of independence, regression, and confusion as to responsibilities—parents quite naturally become overprotective and want to take over, which often causes conflict. Changes in social relationships are common, especially if the situation creates distancing from peers and other significant people in their lives. Adolescent and young adult patients are on the imminence of autonomy, starting to gain success at independent decision-making, when the diagnosis of cancer throws them back to a dependent role with parents and authority figures [6]. They usually have become distanced from their nuclear family but have not yet developed a network of adult support relationships, and have many new roles they are just trying to master when the illness is diagnosed. With limitations in peer-group interaction, social and financial independence, and sexual maturity, it is difficult for adolescents and young adults to establish functional roles in life with regard to careers, relationships, and lifestyles [9]. For most young people, the development of identity and autonomy is accompanied by a sense of immortality and the opportunity to determine their own future, nevertheless for those with life-threatening illness, mortality may be a reality and the future can be determine by limitations instead of possibilities [10]. These patients can feel increasingly isolated with no sense of meaningful future. It is difficult to plan and begin their future when they suddenly realize that they may not have one—they may not graduate, finish their education, keep their friends, get a good job, marry, have children, or become whatever they aspire to be.

Young people with cancer are mentally alert and fully understand their disease, prognosis and the implications for both themselves and their family. They may not, however, have established mechanisms to cope with the anxiety and uncertainty [11]. Feelings of anger and grief at being ill, distress about medical procedures, worries about family members, depression caused by separation from friends and normal activities, and fears of death are common. Many of the adverse side effects of cancer therapy can be overwhelming to these patients' self-image—weight gain or loss, alopecia, lack of energy, acne, delayed sexual maturity, and mutilating surgery are examples of consequences that can be devastating for them [7]. Adolescent and young adult patients often agonize over their personal appearance and hate to be singled out or to appear different. At a time when peer group acceptance and support is so important, they may feel increasingly ostracized [12]. Peer group approval and the need to conform may actually force patients to hide their feelings and emotions—they may, once again, find themselves isolated or act out risk taking behavior in an attempt to gain peer group acceptance [13]. Young patients are particularly vulnerable to developing difficulties throughout the treatment period of a cancer experience and subsequent to treatment completion. Potential adherence and compliance difficulties should be identified before starting or during treatment. If these problems arise, better monitoring should be employed [14, 15]. Increasing availability of psychosocial support, improving communication with health professionals, and generating flexibility in treatment plans are some strategies that may promote treatment adherence and compliance [16]. Other important challenges include the time away from school, work, and community that treatment inevitably requires. School absence results in educational disadvantage and delayed preparation for higher education or career progress [17]. The same holds true for young adults in their work and social worlds, when employment becomes disrupted, when they experiment prejudice and discrimination, when they feel uncertain of how much to disclose about their disease to employers, colleagues and friends [4]. Adolescents should be encouraged to participate in school activities as fully as possible, since positive school experiences help them feel academically accomplished and socially accepted. A similar approach should be assured with young adults to help them re-establish normal life patterns and a renewed sense of control and stability.

The impact of a diagnosis of cancer and its treatment, on both psychosexual identity and fertility can be potentially devastating for teens and young adults. Although these patients may shift their priorities and focus, particularly around the disease, it is crucial to acknowledge that they are still individuals with emerging sexual identities and practices [18]. Adolescence and adulthood is a period when sexuality, intimacy, and reproduction are central. Young people with cancer, however, may feel or look unattractive, may be uninterested in or unable to have sex, and moreover, may be infertile. Thus, there is a significant need to address the potential impact of the diagnosis and treatment on psychosexual maturation and identity development, as well as, the risk to fertility. Distinguish between the issues of sexuality and fertility in the context of an age-appropriate assessment is of utmost importance [19]. In turn, honest communication and objective evaluation are fundamental in guiding young patients and their family in decision making around fertility [20, 21].

There are certain rites of passage that most young people will experiment with, in order to assert their status within society, which is measured in terms of peer acceptance [22]. They may just experiment once—tobacco, alcohol, and/or drug—to challenge adult rules and test their mortality, or they may go further, taking risks with their health. Young patients generally know that consuming drugs and/or alcohol is not the best option for them during treatment. Yet, peer group pressure can be powerful, and many of them will continue to use drugs and alcohol for this or other reasons [19]. Thus, these important issues must be taken into account when treating and caring for this age group with cancer. Questions about past and present alcohol and drug use should be part of a full medical history, and discussions should be held in a sensitive, nonjudgmental, and confidential manner to ensure that patients feel safe to disclose.

After Treatment

When treatment ends, adolescent and young adult patients experience a time of ambivalence—positive feelings that treatment is over, but concern over the loss of support of the health care team and uncertainty over the future. They are also faced with rebuilding versus returning to their previous lives because their perspectives have changed as a result of the cancer treatment. Young patients do not always expect physical and emotional recovery to take as much time as it does, which it often is a source of frustration and distress [23]. After treatment, teens and young adults commonly express difficulties identifying with friends, as they often miss out on experiences that their peers are enjoying: going to school/college, leaving home and establishing independence, pursuing employment, dating, or getting married. Late effects associated with treatment, including cognitive problems, organ dysfunction, growth disturbances, and infertility can affect identity, behaviors, attitudes, and developing sexual function in adolescents and young adults [24]. Furthermore, altered perceptions of body image and self-esteem, changes in relationships, and other social life challenges also may influence sexual activity [25]. Young cancer survivors often report negative feelings about their own attractiveness and sexuality, pessimism about their future relationship possibilities, and uncertainty regarding disclosure of their cancer history to new acquaintances, employers and partners [26, 27].

Although, the existing literature reveals that most adolescent and young adult survivors function well physically and psychologically, a significant subgroup of survivors suffers psychosocial sequelae that continues for many years after treatment is completed—they express concerns about their own health and the health or cancer risk to children they may have, about life goals, finances, job discrimination, difficulties obtaining health insurance, and relationship/affective maladjustment [28, 29]. Young people have greater capacity to understand the severity of their illness, and therefore may experiment persistent distress and anxiety over recurrence and death (the Damocles syndrome) [30]. Despite these problems, however, adolescents and young adults also may demonstrate considerable resilience and adapt successfully in the face of cancer threatening context [31, 32].

In sum, is debatable whether the cancer experience in this population causes difficulties with adult adjustment or whether it allows young patients to grow into stronger people [33]. Professionals have recognized the importance of long term follow up for adolescent and young adult cancer survivors and efforts are concentrated on monitoring the physical consequences of treatment. Yet, more attention needs to be given to psychosocial screening and education regarding a healthy lifestyle—responsibility for progress in young adulthood survival can only be justified if there is quality to this age's group survival [34]. For those patients treated in pediatric services, a formal transition of care to adult-focused survivorship services is needed to meet the unique medical, developmental, and psychosocial challenges of the young adult survivors. It is essential that preparation for the transition starts well in advance, and that the patients and their families are supported on both a practical and emotional basis [10, 35].

Unfortunately, regardless of the increased survival rate, some adolescent and young adult patients still relapse or have recurrences, and others still die. In these circumstances, the tasks involve a shifting toward decisions about new treatment, decreasing survival rate, and moving toward use of palliative care. Adolescents and young adults with advanced or terminal cancer clearly have distinctive medical and psychosocial needs that may not have been adequately provided by either pediatric or adult palliative care services [36]. Teens and young adults see themselves as immortal and have a compulsive need to prove that they are invincible [37]. Thus, if they are mature enough to understand that death is permanent and irreversible, they have great difficulty in confronting it. Young people experience many losses while leaving childhood behind and progressing into adulthood—facing a terminal illness, their sense of loss encompasses both the loss of the past and the loss of the future. For all that, there is growing consensus that palliative care for adolescent and young adult patients should be provided by a multidisciplinary team with expertise in understanding the developmental, psychosocial, and emotional issues that are unique to this age group [38]. A coordinated multidisciplinary effort is crucial in working with these patients and their families to relieve physical and emotional suffering, and to facilitate difficult end-of-life issues, such as treatment cessation, sedation, and place of death [39]. Developing trust and being flexible are key skills to be used with young people receiving palliative care. Although adolescent and young adult patients usually are not making life and death decisions in isolation, at this time, probably more than at any other in the disease trajectory, they need to feel in control. Young patients must be given the opportunity to express sadness and anger, as well as to discuss about death and other end-of-life issues [40]. Finally, exploring individual preferences and providing interventions specific to the needs of terminally ill adolescent and young adult patients could significantly improve end-of-life care. Adapt physical facilities in hospitals and/or hospices, and enhance support for palliative care at home to meet their needs, for example, may be of utmost importance [41••].

Interacting With Adolescents and Young Adults With Cancer

Relationships with parents can be particularly complex for young patients with cancer. Because of health impairment, they tend to become more dependent upon their parents, at least temporarily. For adolescents and young adults, this may involve regression from recently achieved independence into a prior dependent relationship. In turn, parents often try to take control, assuming that they are too unwell to be given autonomy, but young patients need to be involved and to understand the implications of what is happening to them [4]. Undermining their freedom, including participation in decision making, may cause antagonism and resentment—patients are then likely to cease to comply and may even give up of treatment. On the other hand, many young people with cancer protect their parents and do not share their deepest feelings with them, perhaps out of guilt for what their parents are going through or just because they cannot see their parents upset [42, 43]. Encouraging parents and young patients to share their feelings, however, may be helpful.

Siblings' relationships can be strong, but the burden of a cancer experience on health siblings can be tremendous [44]. They may appropriately complain of anger, displacement, injustice, loneliness, and vulnerability, as parents have insufficient time for them [42]. Without adequate support, these feelings can cause resentment and disruption of their relationship with the ill sibling.

For many young patients links with peers are lost through school absence, hospitalization, friends being overwhelmed by the illness or developing new relationships [27]. Family and carers, almost inevitably, become their main source of social support and companionship. Patients should be encouraged to take part in social activities—interaction with peers is essential to minimize feelings of separateness and isolation [45].

Adolescents and young adults are a unique group to work with and staff team must have an interest in, and a commitment to working with this age group. They must have a wide range of knowledge and competencies, which include skills and understanding of the adolescent and young adult developmental stages, the rights of young people (issues around consent, decision making, ethical dilemmas), the ability to communicate and empathize (listening skills and nonverbal communication), the need to work with reference to families, partners, and close friends, the management of nonadherent behavior, the psychosocial and spiritual needs, the importance of liaison with school/college and workplace, and the effects of loss and bereavement [46]. Professionals, especially less experienced ones, may find it particularly hard to cope with the emotional demands of caring for adolescent and young adult patients and will need regular support and supervision [47]. The powerful feelings young people often need to explore, grieving future losses and trying to make sense of their life in the context of illness and premature death, can be emotionally exhausting for health care team—self-awareness and maintenance of professional boundaries is essential to avoid exceeding emotional involvement [48].

Optimal Care for Adolescents and Young Adults With Cancer

Adolescents and young adults with cancer are a distinct subgroup of patients within oncology. From the onset of symptoms until the completion of therapy and beyond, they face physical, psychological, and social challenges that are significantly different from those of adults and children. Despite advances in cancer detection and treatment over the past several decades, however, survival rates and quality of life outcomes for this population have not improved to the same extent that have for younger and older patients [49••]. Suboptimal knowledge of and access to specialized care, inconsistent referral practices, low accrual onto clinical trials [50, 51], poor adherence and tolerance to therapy, disagreement in treatment and follow-up care, and lack of psychosocial support or education programs for adolescent and young adult patients appear to be possible reasons for this reality [41••, 52, 53]. Thus, to enhance quality of care and quality of survival for young patients with cancer, providers must address their specific health and psychosocial needs—the model of optimal care should incorporate medical care, psychosocial support services, and physical environment that are age-appropriate [49••]. The following recommendations may help to improve treatment outcomes, survival rates, and quality of life for this age-specific population: timely detection; efficient processes for diagnosis, initiation of treatment, and promotion of adherence; access to health care professionals with specific knowledge of the young people medical and psychosocial needs; participation in clinical trials and dedicated research; and ideal physical environment [54•]. Above all, flexibility and choice in service provision is important, with young patients making decisions whenever possible.

Conclusion

Going through adolescence and young adulthood is difficult enough, even when all is well and health is not limiting. Accordingly, young people diagnosed with cancer face additional challenges because of the intersection of the cancer experience with the developmental tasks associated with this period. While cognitive and emotional changes drive them to pursue individuality and independence, their opportunities to experience and achieve this are limited. The adolescent and young adult sense of immortality and freedom that shapes one's future is often replaced by increasing dependence and the reality of what will never be achieved. Therefore, cancer-related issues such as confrontation with mortality, changes in physical appearance, lack of independence, disruptions in social life and school/employment, loss of reproductive capacity, anxiety over recurrence, death or late effects are particularly distressing for adolescents and young adults [27]. Given the undesirable life disruptions experienced by this age group, a critical task of the recovery process is to regain a sense of control over their lives as a means of reaching long-term adjustment and well-being. Psychosocial interventions should enable these patients to overcome the detrimental impact of a life-threatening illness and strengthen the internal and external coping resources available to them.

There is a large gap in the provision of palliative and terminal care for adolescents and young adults. Professionals should identify the particular needs of this population and the potential barriers/solutions to improvement of care in the context of palliation and symptom management. It is expected that, if the patient and family are supported, and symptoms are managed appropriately, there will be less comorbidity for all people involved [36].

Interacting with adolescents and young adults with cancer is a critical issue throughout a continuum of care from diagnosis to off-treatment survival or end of life. Relationships with parents, siblings, and peers are particularly complex. Staff team caring for young patients must be dedicated to working with this age group and should have a wide range of basic knowledge and competencies. It is important that they are aware of the difficulties faced to "normal" adolescence or young adulthood and how cancer diagnosis impacts on these, not only for the patient, but also for their parents, siblings, partners, and significant others. In the face of life-threatening illness, a well-coordinated multidisciplinary approach is essential to help families and carers to allow young patients to make the transition to adulthood, and to support them as they recognize the reality of goals that cannot be achieved. Because of the emotional demands of adolescent and young adult patients, all professionals involved in their care should receive training, regular support, and supervision.

Finally, adolescent and young adult cancer patients should be viewed as a distinct age group that has unique medical and psychosocial needs. Ideally, specialized adolescent and young adult oncology units should be developed in the expectancy that the centralization of care, the availability of age-targeted clinical trials, and the focused attention on the unique psychosocial needs of this population will lead to improved their treatment, survival and quality of life.

Compliance with Ethics Guidelines

Conflict of Interest Claudia L. Epelman declares no potential conflict of interest.

Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.

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