Recreation Programming for the Adolescent with Cancer

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This article presents a model recreation program for adolescents with cancer, that has been designed to address the psychosocial impacts of the disease on the adolescent and the family. Following a discussion of the effects of a cancer diagnosis, the program components will be described, with suggestions for future research.

Cancer is a disease that affects all people regardless of culture, socio-economic background, race, gender, and age. Although cancer is rare among those younger than 20 years of age, childhood cancers rank fourth as a cause of death (Gloeckler-Ries, Percy, & Bunin, 1999). Although over the past two decades childhood cancer mortality has declined dramatically, unfortunately, the rate of cancer incidence among adolescents, in the United States, has increased from 183 per million in 1975-79 to slightly over 203.8 per million in 1990-95 (Smith, Gurney, & Gloeckler-Ries, 1999). According to the National Cancer Institute (1999), the incidence of cancer among adolescents (1519 year-olds) is substantially greater than the incidence of cancer among children younger than 15 years of age. Survival rates for adolescents with cancer vary depending on the type of cancer from 22% for individuals with acute myeloid leukemia to 90% for those with Hodgkin's disease-germ cell tumors, thyroid carcinoma, and melanoma (Smith, Gurney, & Gloeckler-Ries, 1999).

Implications of a Cancer Diagnosis

The age at which a child is diagnosed with cancer has been shown to be an important factor in long-term psychosocial adjustment with adolescents reporting more psychosocial difficulties that younger children (Noll, Bukowski, LeRoy, Rogosch, & Kulkarni, 1991; Koocher, O'Malley, & Foster, 1981). According to Erikson (1963), adolescence is a time of physiological revolution with rapid body growth and sexual maturation which forces one to begin the task of establishing independence from parents and family. These bodily changes have profound consequences, particularly because body image is at the core of the overall self-image (Siegel, 1982). The adolescent wants to avoid being "different" from his/her peers at all costs, particularly because physical appearance, body image, and peer conformity are important derivatives of self-esteem (Davis, Anderson, Linkowski, Berger, & Feinstein, 1991).

Kellerman and Katz (1988) and Adsett (1973) observed that adolescents who were disfigured from cancer therapy (e.g. facial disfigurement, loss of limb) had a greater fear of unacceptability and isolation secondary to their fear of death itself or of a recurrence of the illness. According to Benjamin (1978), the worst that can happen to the adolescent is to be considered different from his/her peers, to be unaccepted. The physical appearances of the illness are the least easily endured at this age; shame, frustration, and the adult mourning process, including isolation and depression, may result.

There are physiological effects related to cancer and its treatment such as hair loss, pain, weakness, sensory impairment, loss of muscle control, paralysis (Children's Brain Tumor Foundation, 1998), nausea, vomiting, constipation, diarrhea (Henderson, 2000), neuropsychological dysfunctions (e.g. memory loss, motor skills, speed), persistent immunodeficiency problem, weight gain/loss (Ducore, Walter, Emslie, & Bertolone, 1993), sterility, incontinence, speech impairment, dysphagia, and fatigue (Kellerman & Barni, 1982). Additionally, a diagnosis of cancer impacts one psychologically, bringing nightmares (McCue, 1994), withdrawal from peers, depression, fear of going to school, regressive behavior (Stjernsward & Colleau, 1996; Kagen-Goodhart, 1977), and fear of dying (Breitbart & Holland, 1993). These physiological and psychological aspects of the disease and treatment are intertwined and highly complex.
Treatment measures which include surgery, chemotherapy, and radiation are administered to assist the adolescent patient in surviving. These treatments are often more disabling and debilitating than the cancer itself and impact the psychological well-being of the patient (Children's Brain Tumor Foundation, 1998). Surgery can result in paralysis, loss of a limb or body part, impaired cognitive functioning, difficulty with swallowing, speech impairments, weakness, and decreased motor functioning. Chemotherapy can result in hair loss, nausea, vomiting, weight loss/gain, sterility, weakness, and secondary tumors, as well as social adjustment with peers (Noll et al., 1991; Larcombe et al., 1991; & Katz, Rubinstein, Hubert, & Blew, 1988) and emotional well-being (Bennett, 1994; Varni, Katz, Colegrove, & Dolgin, 1995; Canning, Hansen, Shade, & Boyce, 1992). During adolescence, when peers are establishing their independence from parents, the adolescent with cancer becomes increasing dependent on parents impacting his/her ability to develop peer bonds (Levin & Hersh, 1982). It is normal for a parent of a child with cancer to become overly protective, controlling, and restrictive which are the very elements that impede an adolescent's achievement of independence (Davis et al., 1991). Radiation also brings major complications which can include loss of intelligence, secondary tumors, and sterility.

Impact of a Diagnosis on Leisure

Cancer and its treatments affect individuals' ability to have spontaneity and joy in their leisure; for many, the concept of perceived freedom in one's leisure is nonexistent. Cancer survivors' perception of independence and spontaneity are compromised by the disabilities incurred and they are much more dependent on family members for participation in recreation activities. For many adolescents, recreational activities and leisure experiences are central to their identity (e.g., singer, basketball player, cheerleader, cook) (Kelly & Freysinger, 2000). Cancer diminishes the opportunities that the adolescent has for leisure participation with peers and for the development of leisure identities, further complicating the adolescent's normal developmental process and increasing feelings of isolation and loneliness.

Very few studies have examined the effects of participation in therapeutic recreation (TR) programs on the physiological and psychological manifestations of cancer and its treatments. One such study (Bost and Brown, 1982) found that patients who participated in TR programs were less stressed, had less anxiety, and were less bored and that active participation provided an outlet for expressions of emotions, opportunities for socialization, and creativity. Kaplan, Rosenstein, Skomorowsky, Shenker, and Ramsey (1981) found that simply offering activities to the hospitalized adolescent was insufficient without trained recreational staff to motivate participation. They found that more than half of the patients spent their time in solitary pursuits or inactivity. Sourby (1998) found that TR provided opportunities for the cancer patient to socialize, maintain a sense of self, express creativity, learn new leisure skills, and ultimately receive enjoyment from life. In one study of 76 children with cancer, ages 8 to 15, the researchers (Noll et al., 1999) found that participants showed no significant differences from healthy children in the areas of loneliness, depression, anxiety, and self-concept; not surprisingly, the children with cancer reported significantly lower levels of satisfaction with athletic competence. The children in this study, however, did receive services that included relaxation, facilitating liaisons and communication with other health care professionals, helping the adolescent to adjust to the disease, support for siblings, the facilitation of patient and family coping skills, and assistance with school reentry.

A Model Program

In 1996, Beth Israel Hospital, located in New York City, created the Institute for Neurology and Neurosurgery (INN). Today, the INN has developed a comprehensive, multidisciplinary center for the diagnosis and treatment of children and adolescents with neurological disorders, primarily brain stem tumors which are in an especially hazardous place to operate. The INN deals with the most difficult cases of brain tumors, deemed inoperable by most physicians. The INN has created a nurturing environment where they "treat" the entire family unit using a variety of health care professionals. At the center of treatment lies the recreation program which approaches the provision of TR services in a holistic manner, providing services to the entire family unit. The recreation program is staffed with four fulltime and two-part time certified therapeutic recreation specialists and child life specialists who are supported by TR and child life student interns and volunteers. This specialized patient-focused care given to children with cancer, including adolescents, has been shown to have a positive impact on overall treatment and psychological well-being of the child with cancer (American Academy of Pediatrics, 1997).
The comprehensive recreation program was established to confront the medical, psychological, and physiological implications of childhood and adolescent cancer and its related treatments. The goals of a recreation program should provide opportunities (a) that reduce anxiety and depression, (b) that increase socialization, (c) that foster independence, (d) to discuss feelings regarding the impact of their illness, (e) for the facilitation of communication regarding health issues between and among family members and health care staff, (f) for easing the transition in returning to community and school, (g) that increase one's ability to cope with the stressors associated with the disease, and (h) to adjust one's recreation activities and interests to their current status.

The recreation program operates seven days a week and is designed with two play rooms, each consisting of kitchen, living, and arts and craft areas, computers, videos games and large screen television; a teen room with computer/internet access, video games, television and VCR, fax, woodworking and other crafts projects, compact disks and player, and board games; and a roof garden/playground with backgammon and chess/checker tables, and sand and water tables for younger children. Each patient bed is equipped with television, VCR, videos, and cassette player/radio. There is a family room for staff to work privately with family members and a parents' room with internet access. The facility is designed to meet the needs of the patients which fall under the following program categories: (a) stress reduction, (b) socialization, (c) patient education, (d) recreation and leisure skill development, (e) leisure awareness and counseling, and (f) special events with family and siblings. These programmatic categories are addressed with a variety of interventions designed to enhance the adolescents' participation and to increase individual levels of satisfaction by focusing on different motivational factors. All activities are chosen for their ability to improve physical functioning, psychological well being, social ability, and leisure life style.

**Stress Reduction Program**

The adolescent with cancer is under a tremendous amount of stress which together with potent treatments, suppresses one's already suppressed immune system. A TR professional in a health care setting must be very familiar with the medical conditions of the illness and with medical terminology. A number of studies have indicated that there is a positive relationship between participation in stress reduction programs and enhancing one's immune system (Caroleo, 1999a; Lasater, 1999; Leserman, Perkins, & Evans, 1992). The recreation program offers a variety of activities designed and recognized to reduce one's stress such as massage, relaxation imagery, meditation, and breathing exercises (Caroleo, 1999a; Lasater, 1999). Other non-traditional methods of stress reduction that simply divert one's attention from their illness, through the use of arts and crafts, video games, music, singing, and movies, to more enjoyable and rewarding experiences have been shown to reduce the levels of stress among adolescents.

**Socialization**

Eduardo, a non English speaking patient, left his native country of Guatemala when physicians there deemed his cancer inoperable. Separated from family, friends, and siblings Eduardo's sense of isolation and loneliness intensified. The staff introduced him to another patient, Richard, who was being treated on an outpatient basis for a similar diagnosis. Richard was similar in age and also happened to speak Eduardo's native language. Once the initial connection was made, they became immediate friends and established their own support network. Today, they remain friends, communicate via email, and when Eduardo returns for periodic treatments, he stays at the home of his friend Richard.

Providing opportunities for the adolescent to socialize with peers diagnosed with cancer is essential in reducing isolation and establishing meaningful relationships. The recreation program has arranged with medical staff to offer outpatient services and treatments for the adolescent on specific days during the week. This allows for the recreation staff to organize adolescent-specific programming and to assist in the development and bonding of peer relationships with other patients. The recreation program has a youth room with Internet access so that when hospitalized, the patient can maintain contact with his/her friends at home.

Using a social setting to provide concrete objective disease and treatment information is frequently viewed as less threatening and provides optimal benefits. Providing opportunities for the adolescent to socialize with peers allows the patient to discuss the disease and treatments with individuals who may have already gone through what he/she will be going through. This assists the individual in reducing preoperative and pre-treatment stress and anxiety while strengthening the bonds among peers. Simply meeting and socializing with a peer who is a survivor reduces stress (Caroleo, 1999b).
Another program component of socialization is the prayer and song group. This group brings together patients, family members, and staff to share individual experiences and needs through prayer in an interdenominational gathering. This activity provides patients, family members, and staff the opportunity to discuss wishes, hopes, fears, and desires. Core issues are discussed in a supportive environment, giving the participants permission to express their feelings of sadness, grief, fear, anger, and love. This group assists in cementing the bonds and validating the feelings shared by all who are affected by the disease.

Patient Education

Mary arrived at the INN for surgery and it was clear from the onset that she was non-communicative, distant, and experiencing a sense of hopelessness. It was learned that Mary believed that her condition was fatal and had heard many untruths about the surgery and treatment process. These untruths terrified Mary and resulted in withdrawal from her family, friends, and peers. The staff provided Mary with the truths regarding the surgery and treatment, introductions to other teens who had gone through the process, a tour of operating rooms and equipment, and assistance in developing a list of questions that she would ask her doctors. With the gift of knowledge regarding treatment, Mary now opened up communication lines and became an advocate for her own health care. Today, Mary assists her peers in similar situations by providing them with accurate information regarding their disease. She even developed and starred in an educational video that addresses the fears, truths, and myths of cancer treatment.

The primary purpose of patient education is to reduce anxiety by providing concrete jargon-free information regarding the disease and treatments and to begin developing a relationship based on open and honest communication between patient and staff. This can occur formally through pre-operative tours and procedural preparation sessions and informally through open discussion in the teen room. Pre-operative tours are generally conducted with the family and can include introducing the patient/family to nursing and other staff that will be working directly with the patient, hospital environment, and equipment. While procedural preparation can be done individually with the adolescent, depending on the patients' level of interest and independence, families are sometimes invited to participate. Johnson (1996) found that providing concrete information resulted in less recreation and pastime disruptions. Adolescents conceptualize disease in terms of what it means in altering their body image and feelings about themselves rather than what they know academically (Carter, Van Andel, & Robb, 1995).

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Patient education, which generally includes working with the patient and his/her parents, should not neglect the needs of the siblings. The impact of a child diagnosed with cancer can be devastating to the entire family. The parents tend to spend less time at home which impacts the amount and quality of time they spend with their other children. The siblings of children with cancer have more somatization (e.g. trouble sleeping and eating, higher tendency of health complaints, headaches, stomach aches), greater incidence of risk-taking behaviors (e.g. alcohol and drug abuse), deteriorating grades, thoughts of running away, and fears of being alone, than do siblings of healthy children (Terzo, 1999). Patient education for the sibling could include information about the brother/sister's disease, etiology, treatment, and outcomes. Parents could be advised of the effects of a child's diagnosis of cancer on the siblings and be encouraged to include the siblings in all services offered by the recreation program.

Recreation and Leisure Skill Development

In her mind, Julie's hopes, desires, and dreams of becoming a fashion designer came to an end when she learned of her diagnosis. While hospitalized, Julie refused to participate in recreational programs, believing that nothing could replace her interest in fashion and a simple sewing group would not suffice. The recreation staff arranged, for Julie, a tour of the garment district including visits with designers, pattern makers, and tailors. At the end of her tour, the designers presented Julie with a professional sewing machine. To Julie, this tour was far more than a sewing machine - the designers reignited her hopes of a career in fashion. Today, Julie maintains contact with the people she met during the tour and spends much of her time designing and sewing her own fashions.

The recreation program offers a variety of recreation and leisure skill development opportunities appropriate to the individual's level of cognitive, physical, psychological, and social functioning. The primary focus of this program is to maintain prior skills and interest and to facilitate the development of new leisure skills. When this takes place, adaptation and modifications are addressed on an individual basis to ensure mastery in the chosen area of interest.
Leisure Awareness and Counseling

The leisure awareness and counseling component focuses on the attainment of appropriate leisure related skills, knowledge, and attitudes (Buskin & Sivan, 1995). This is accomplished through small groups and one-on-one interactions between the staff and the patient. Discussions center on the importance of leisure, leisure awareness, individual leisure interests, and decision making in leisure. The goal here is to experiment with new leisure roles/interests appropriate to the individual's physical and psychological abilities. The focus is on the individual's abilities and on helping the patient to see him/herself as a whole person with needs, skills, dreams, and hopes.

Special Events with Family and Siblings

Special events are used to motivate patients and families to come together to celebrate holidays, birthdays, end of chemotherapy, post surgery, the culmination of a process, and life in general. These events occur regularly to break routine and foster the development of bonds among parents and families in a no threatening environment. These events can include theme events such as Wizard of Oz, Star Wars, and sports; manicure and beauty events; and trips to the theater, sporting events, and picnics. Additionally, the recreation program organizes special events around celebrity visits such as Miss America, Magic Johnson, Dali Lama, NY Jets, and NY Knicks.

Concluding Remarks

Recreation plays a vital role in the care and treatment of the adolescent with cancer, providing him/her with a sense of normalcy, stability, mastery over the environment, motivation for continued treatment, and a positive context for living. Recreation provides opportunities for the youth to socialize with peers, express oneself, learn and develop new leisure skills, develop coping strategies, and maintain enjoyment and satisfaction with one's leisure. Unfortunately, very little research has been conducted and published that addresses the hospitalized adolescent (Clarke & Clarke, 1999). Research is needed in the following areas: (a) the impact of cancer and its treatments on adolescence and how leisure and recreation can assist in the coping process, (b) the recreational and leisure needs of the hospitalized adolescent, and (c) the impact on siblings when a brother or sister is hospitalized and how recreation can assist them in coping.

The care of a child with cancer evokes significant emotional stress in the caregivers, both family and recreational professionals who attend to them. Too often the stress of the recreational professional goes unacknowledged because of concerns about providing optimal and satisfying services to the child and family. The stress experienced by the professional, if unrecognized and unacknowledged, can parallel or even supplant that experienced by the patient's family (Fulton, 1989). Virtually no research has been conducted that examines the impact of working with children and adolescents with terminal illness on the recreation professionals’ free time and leisure participation.

The recreation professional will continue providing services to adolescents with cancer and their families. In order for the field to provide the highest standard of excellence in our service delivery, it is imperative that research be conducted and programmatic information be published in this area to guide and direct the development of TR programs and to ensure that the specific needs of this population are addressed appropriately.

References


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