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Safety lies at the core of the care we deliver. However, there are so many factors that affect patient safety, and these are not always within our control. These include communication breakdown, failure to escalate the chain of command during a life-threatening emergency, systems issues, and nurse-patient staffing ratios, to name just a few. Nurses are unique within the health care system in that they coordinate, implement, and evaluate the patient care that is administered by the entire team on an ongoing basis.

All of us personally want safe health care, and most assuredly we want to make certain that our patients have safe care. However, the current lexicon sometimes uses the term safe interchangeably with quality. The two adjectives are similar but not identical. Safe care is care administered without errors that have a negative impact on the patient’s well-being. Safe care has objective parameters.

Quality care, on the other hand, connotes excellence and is subjective. Patients might believe they have quality care if someone fluffs their pillow regularly. Bedside nurses might believe that their patients receive quality care if they get their medicines and treatments on time. Nurse managers might believe that quality care is delivered if it conforms to established pathways or guidelines. Nevertheless, the emphasis is on safety, which is the sine qua non, the absolute prerequisite and goal to which all of us must work as we improve our health care delivery system.

Nurses, as well as other providers, have individual responsibilities to be safe, competent practitioners. More than that, they must be involved in working collaboratively to sort out systemic and professional issues affecting safe care. Policy makers influence patient care outcomes with legislation, such as that designed to create error-reporting systems and change the work environment. Professional societies develop practice standards and guidelines and codes of ethics that underpin the education and practice of the members of their discipline. Accrediting agencies, such as the Joint Commission on Accreditation of Healthcare Organizations, set safety standards and goals.

Since mid-2003, the Association of Pediatric Oncology Nurses (APON) has been developing a chemotherapy provider program for pediatric oncology nurses to this end. This program, titled the “Pediatric Chemotherapy and Biotherapy Provider Program,” will have four distinct components. Robbie Norville is serving as the pediatric chemotherapy and biotherapy curriculum team leader and is coordinating and assembling the chapters that will make up the text that will drive the program. Melissa Silva is the team leader who is overseeing the development of a provider program and will lead the team by organizing lectures and lecture materials to be used during training. Deb Echtenkamp is coordinating and leading the development of an instructor program to train nurses to teach the curriculum. Jennifer Harley is the pediatric chemotherapy and biotherapy Web program leader, organizing the material in an electronic format, as this material will eventually be available online.

The first Pediatric Chemotherapy and Biotherapy Provider and Instructor training will be available to APON members as a preconference offering in Kansas City in October 2004. The goal of this program is to train nurses regarding pediatric chemotherapy administration,
thereby promoting patient safety and improve quality of care. These nurses will be able to return to their home institutions and provide ongoing training as needed to new staff.

You will be hearing more about this program in the coming months. The APON leadership realizes the importance of the role of the professional association in setting standards for safe delivery of nursing care and is facing one of the safety in health care challenges head on.

Nancy E. Kline, PhD, RN, CPNP, FAAN

Editor in Chief
The purpose of this descriptive study was to determine the levels of total fungus (TF) and Aspergillus in a pediatric hematopoietic stem cell transplant (HSCT) unit. One hundred twenty air samples and 120 floor samples were collected from the same locations in 10 patient rooms and bathrooms for 4 consecutive days. The count in colony-forming units of TF and Aspergillus from each of the samples was measured by the institution’s mycology laboratory. Means, standard deviations, minimum values, and maximum values were determined for levels of TF and Aspergillus from different locations and on different days in the air and on the floor. Determination of a mean value of TF and Aspergillus for each room allowed for analysis of mean values of TF and Aspergillus for sample category, room side, room type, and room status. After visual examination of the mean values for the air samples collected, it was determined that the TF and Aspergillus in the air were less than the institution’s acceptable air baseline standard. t tests and analysis of variance were used to verify the findings.

Key words: fungus, Aspergillus, HSCT, pediatrics

Some of the most vulnerable and immunocompromised patients are those that undergo hematopoietic stem cell transplantation (HSCT). Many complications are due to opportunistic infections that affect these patients when they are most vulnerable. Despite aggressive treatment measures, invasive aspergillosis (IA) is difficult to eradicate and oftentimes fatal. Even when treatment is deemed successful, IA has the propensity to reactivate, especially in the setting of prolonged immunosuppression (Kontoyiannis & Bodey, 2002). Some believe there is a dormant, quiescent Aspergillus that is activated to a pathogenic status in the setting of immunosuppression (Paterson & Singh, 1999; Richardson et al., 2000; Warnock, 1991). Little is known of the time lapse between fungal contamination and the occurrence of IA in neutropenic patients (Alberti et al., 2001).

Treatment of fungal infection is suboptimal, and therefore prevention is of utmost importance. The most important prophylactic measure against IA involves decreasing the quantity and variety of fungi that enter into contact with patients. Prevention must be aimed at elimination of fungi from the environment.

To ascertain if preventive measures are effective, surveillance measures including periodic, random sample collection for total fungus and Aspergillus must be done. Measurement of fungal presence in the hospital environment evaluates the efficiency of the preventive measures adopted as institutional environmental safeguards.
Purpose

The purpose of this study was to obtain air and floor samples to detect the environmental presence and level of total fungus and *Aspergillus* on a pediatric hematopoietic stem cell transplant unit. Fungal infection has been documented as a resilient, opportunistic infection in immunocompromised patients (Centers for Disease Control and Prevention, 2000). *Aspergillus* is a major cause of morbidity and death in patients with hematological malignancies or HSCT (Kullberg & Lashof, 2002; Martino & Subira, 2002).

The environment has been implicated in playing a pivotal role in the epidemiology of IA. Preventive measures are based on the elimination of *Aspergillus* from the environment, thereby decreasing exposure to this pathogen in the hospital setting. According to Martino and Subira (2002), the most important currently available prophylactic measures against invasive fungal infection involve reducing the quantity and variety of fungi that enter into contact with patients during their most vulnerable periods. According to the Centers for Disease Control and Prevention (2000), prevention of these fungal infections is preferable to the insufficient treatment that is presently available. Therefore, surveillance of the hospital environment should include periodic, random sample collections for the determination of total fungus and *Aspergillus* levels on the HSCT unit.

Research Questions

Research Question 1: What are the levels of total fungus and *Aspergillus* of air and floor samples obtained from patient rooms and bathrooms on a pediatric HSCT?

Research Question 2: Are the levels of total fungus and *Aspergillus* obtained from the air samples less than or equal to the accepted institutional air baseline standard?

Research Question 3: Are there differences in total fungus and *Aspergillus* levels among sample category (air or floor), location (patient room and bathroom; see Tables 1 and 2 for specific locations), day of week, room side (west, north, east), room status (occupied or unoccupied), and room type (isolation or non-isolation)?

Background and Significance

The suspicion of infection with *Aspergillus* invokes a dismal and pessimistic outcome for those patients who are immunocompromised and vulnerable to life-threatening infections. Adult studies underscore the grim findings for the patient with fungal infection. According to Hajjeh and Warnock (2001), invasive aspergillosis affects 28% of patients who have undergone allogeneic stem cell transplantation. Perfect et al. (2001) found that management of IA remains incomplete: Only 38% of allogeneic transplant patients are alive 3 months after the diagnosis of IA. Furthermore, only 40% of patients who received amphotericin-B for treatment of IA were alive at 3 months. The overall case fatality rate (CFR) reported by Lin, Schranz, and Teutsch (2001) was 58%. The CFR was highest for bone marrow transplant recipients (86.7%) and for patients with central nervous system or disseminated aspergillosis (88.1%). The crude mortality rate as reported by Kontoyiannis and Bodey (2002) remains high. Ten percent of all deaths in patients who undergo allogeneic transplant are attributed to IA, which has a mortality rate of 90% in this setting. Failure of antifungal therapy was seen in 85% of the patients who had IA, the majority of whom died within 6 weeks. Furthermore, according to Dasbach (2000), the financial burden of IA-associated hospitalization is enormous: U.S. data from 1996 estimated the total cost of IA treatment to be $633 million, with an average cost per case of $65,000.

Institutional data from 1997 to 2002 were reviewed to determine the most current experiences with *Aspergillus* infection. There was a hospital-wide total of 57 aspergillosis cases documented. Of these 57 patients, 32 (56%) involved allogeneic transplant recipients. Of all the *Aspergillus* cases reported, 23% were considered nosocomial and 77% were considered community acquired. From 1997 to 2001, there were 51 nosocomial infections attributed to fungi. Infections reported included *Candida tropicalis*, *Aspergillus fumigatus*, *Malessezia furfur*, and *Cunninghamella* species.

The HSCT Patient

Hematopoietic stem cell transplant recipients are at greatest risk for the acquisition of fungal infection and invasive aspergillosis. HSCT treats diseases caused by hematologic malignancies, blood dyscrasias, solid
tumors, bone diseases, immunologic disorders, and congenital enzyme deficiencies (Centers for Disease Control and Prevention, 2000). Oftentimes, due to the very nature of the underlying disease requiring treatment with stem cell transplantation, the patient is already experiencing immune dysfunction. Complicating and exacerbating this process is the ablative conditioning regimens given prior to transplantation. The risk of acquiring a life-threatening invasive fungal infection is related to the intensity of the cytotoxic regimen and the duration of the resultant neutropenia (Bow et al., 2002; Fridkin & Jarvis, 1996; Kontoyiannis & Bodey, 2002; Marr, Carter, Crippa, Wald, & Corey, 2002; Martino & Subira, 2002; Warnock, 1991). These risk factors are reflected in a bimodal time distribution for the development of IA (Marr et al., 2002; Martino & Subira, 2002; Paterson & Singh, 1999). These risk factors are reflected in a bimodal time distribution for the development of IA (Marr et al., 2002; Martino & Subira, 2002; Paterson & Singh, 1999). Approximately 40% of patients develop IA around 2 weeks after transplant while neutropenic, before engraftment. A second peak of infection occurs approximately 100 days posttransplant while receiving graft versus host disease prophylaxis and treatment. Auner, Sill, Mulabecirovic, Linkesch, and Krause (2002) reported that patients with total body irradiation (TBI) as part of their conditioning regimen had more infections due to longer duration of neutropenia in the early posttransplant period than patients without TBI.

The average duration of neutropenia for autologous and allogeneic transplants in this pediatric HSCT unit is 7 days and 22 days, respectively. The duration of this neutropenia determines length of stay. This extended time frame increases the exposure of the pediatric HSCT recipient to the hospital environment.

These conditioning regimens destroy normal hematopoiesis for neutrophils, monocytes, and macrophages. Damage to mucosal progenitor cells causes a temporary loss of mucosal barrier integrity. Virtually all HSCT recipients rapidly lose all T and B lymphocytes after conditioning. Even with successful engraftment, the recipient will not regain normal immunologic function for 6 to 12 months.

The use of immunosuppressive agents such as cyclosporine and mycophenolate to prevent and treat graft versus host disease inhibits T-cell and B-cell growth and function. Corticosteroids decrease the number of circulating T cells and B cells and has harmful effects on macrophage and neutrophil function that suppress the inflammatory response (Baddley, Stroud, Salzman, & Pappas, 2001; Kullberg & Lashof, 2002; Martino & Subira, 2002; Warnock, 1991). Suppression

### Table 1. Total Fungus and *Aspergillus* at Different Locations in the Air

<table>
<thead>
<tr>
<th>Fungus Type</th>
<th>Location</th>
<th>M</th>
<th>SD</th>
<th>Minimum</th>
<th>Maximum</th>
<th>p Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total fungus</td>
<td>1</td>
<td>2.599</td>
<td>1.999</td>
<td>0.835</td>
<td>8.375</td>
<td>.0335</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>2.178</td>
<td>1.601</td>
<td>0.5</td>
<td>5.875</td>
<td></td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>4.325</td>
<td>2.158</td>
<td>1.625</td>
<td>9.000</td>
<td></td>
</tr>
<tr>
<td><em>Aspergillus</em></td>
<td>1</td>
<td>0.011</td>
<td>0.038</td>
<td>0</td>
<td>0.125</td>
<td>.0824</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>0.034</td>
<td>0.058</td>
<td>0</td>
<td>0.125</td>
<td></td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>0.106</td>
<td>0.157</td>
<td>0</td>
<td>0.500</td>
<td></td>
</tr>
</tbody>
</table>

NOTE: Location 1 = first complete floor tile, facing room; location 2 = left side of bed, midline, and facing the head; location 3 = bathroom midline.

### Table 2. Total Fungus and *Aspergillus* at Different Locations on the Floor

<table>
<thead>
<tr>
<th>Fungus Type</th>
<th>Location</th>
<th>M</th>
<th>SD</th>
<th>Minimum</th>
<th>Maximum</th>
<th>p Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total fungus</td>
<td>1</td>
<td>4.553</td>
<td>3.945</td>
<td>1</td>
<td>12.5</td>
<td>.0197</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>4.765</td>
<td>4.049</td>
<td>1</td>
<td>14.0</td>
<td></td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>1.045</td>
<td>0.384</td>
<td>0.5</td>
<td>1.5</td>
<td></td>
</tr>
<tr>
<td><em>Aspergillus</em></td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>.1574</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>0.295</td>
<td>0.669</td>
<td>0</td>
<td>2.25</td>
<td></td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>0.023</td>
<td>0.075</td>
<td>0</td>
<td>0.25</td>
<td></td>
</tr>
</tbody>
</table>

NOTE: Location 1 = threshold, first complete floor tile; location 2 = below left corner of window seal; location 3 = bathroom, left of commode.
of cell-mediated and humoral responses contributes to the predisposition of pediatric HSCT recipients to fungal infections (Marr et al., 2002; Martino & Subira, 2002; Warnock, 1991).

General risk factors for fungal infection common to HSCT recipients are the use of central venous catheters, total parenteral nutrition, broad spectrum antibiotics, and prolonged hospitalization (Ellis, 2001; Fridkin & Jarvis, 1996; Soubani & Chandrasekar, 2002). The use of these supportive measures is required throughout the transplantation process until engraftment and discharge occurs. Return admissions to the hospital are common after the initial discharge until the patient’s immune status becomes more stable.

In conclusion, patient immune characteristics should be recognized so that relationships to predisposition and acquisition of fungal infection can be made. The manipulation of the immune system and the supportive treatment required predisposes the pediatric HSCT patient to life-threatening opportunistic infections. Until the hematopoietic system recovers, the patient is very vulnerable to invasive disease after exposure to pathogenic fungi in the environment.

**Conceptual Framework**

The interplay of the HSCT patient, the organism, and the hospital environment is depicted within the wider community environment. Characteristics of each of these entities contribute to the predisposition of HSCT patients to invasive aspergillosis. The traits and the evasive abilities of the organism, the risk factors inherent to HSCT treatment, and the potential sources of Aspergillus in the hospital affect the potential for infection (see Figure 1).

Incomplete knowledge of the etiology of Aspergillus infection is apparent. It is difficult to determine if an Aspergillus infection is nosocomial or community acquired. Prevention of community-acquired infection poses even greater challenges. The incubation period of Aspergillus is uncertain. Some suggest that there is a dormant colonization with Aspergillus that becomes invasive and pathogenic in the vulnerable host.

Hospital environmental measures are present to decrease the likelihood of Aspergillus transmission to the immunocompromised HSCT patient (see Figure 2). Pharmacological and supportive measures are used to provide prophylaxis and treatment against fungal infection and to decrease the period of neutropenia after transplant.

Despite these environmental precautions, supportive measures, and antifungal agents, Aspergillus continues to infect patients and remains a difficult disease to detect, diagnose, and treat. Because treatment of disease with existing antifungal agents is suboptimal, it is imperative that efforts be aimed at prevention. Until diagnostic methods and pharmacological agents are more effective, prevention must be aimed at elimination of fungi from the environment.

**Design**

A descriptive study design was used to assess and provide an accurate portrayal of the levels of total fungus and Aspergillus of 120 air samples and 120 floor samples collected from a pediatric HSCT unit. These samples were obtained from the same locations in 10 patient rooms and bathrooms over 4 consecutive days. The level of total fungus and Aspergillus from each air sample and each floor sample was determined and reported in colony-forming units (CFUs) by the Mycology Laboratory of the Clinical Microbiology section of the Department of Pathology.

**Setting**

The investigation took place within a pediatric hematopoietic stem cell transplantation unit located...
on the fourth floor of a major pediatric research hospital. The unit specializes in autologous and allogeneic stem cell transplantations. Average patient length of stay varies according to treatment protocol and type of transplant. Allogeneic transplantation is associated with a greater length of stay than is autologous transplantation.

The number of organisms to which the susceptible patient is exposed is a factor in the establishment of infection. The infection control guidelines as outlined in the institution’s Procedure Manual for Infection Control for the HSCT unit are strictly taught to personnel and families and are followed by all who enter the unit. There is an attitude of infection awareness on this HSCT unit, and deviations from infection control policies are not tolerated or ignored.

Sample

The sample consisted of 120 air samples and 120 floor samples collected from the same locations in 10 patient rooms and bathrooms over 4 consecutive days. The selection of patient rooms and bathrooms was based on patient census and room status. All occupied rooms were included in the sample collection. Seven rooms were occupied, and three rooms were unoccupied during collection of the air and floor samples. The determination of total fungus levels and Aspergillus levels in CFUs was then made by the Mycology Laboratory of the institution’s Clinical Microbiology Section of the Department of Pathology.

The air samples and floor samples were collected from the same locations each day. The three floor samples from each room each day were obtained from the threshold, below left corner of window, and from bathroom to the left of the commode. The locations for the three air samples collected from each room each day were obtained from the threshold facing into room; beside patient bed, midline, and facing the head; and from the midline of the patient bathroom.

Instruments

Brain Heart Infusion Plates With Gentamicin

Brain heart infusion 150 mm diameter plates with gentamicin were used as the medium for fungal growth of the air samples and floor samples collected. This growth medium has always been used by the institution to measure levels of total fungus and Aspergillus. The use of these plates allowed more reliable comparisons to historical total fungus and Aspergillus level findings obtained by the institution.

Instruments for Floor Samples

A plastic template measuring 10 inches by 10 inches was used for the collection of the floor samples. The template was placed on the floor for each of the three locations to ensure that the same area (10 × 10 inches) was swabbed for each floor sample obtained. Cotton-tipped applicator swabs were moistened with normal saline and used for collection of the floor samples. Test tubes measuring 16 × 25 mm containing 1 cc of normal saline were used for the transport medium.

Instruments for Air Samples

Collection of the air samples was done using the Staplex Company air-sampling device using 1-micron felt filters. Passing air through a filter causes particles to be trapped on the filter medium. A gauge on the device to measure the pressure against the filter was used, and a time chart was consulted to determine how long the device must be on to run 2 m³ of air through the filter with each sample collected. A stopwatch was used to time each air sample collected. This is important to ensure that each air sample collected consistently represents the presence of total fungus and Aspergillus from 2 m³ of air each time.
Procedure

Sample collection occurred for 4 consecutive days in April 2002. Two floor samples and two air samples were obtained in 10 patient rooms from the same location each day. One floor sample and one air sample were obtained in the 10 patient bathrooms from the same location each day. Because fungal conidia can be transported on fabrics, the investigator changed protective gowns, gloves, and masks for each room sampled to decrease the likelihood of unintentional contamination (Mitka, 2001; Neely & Orloff, 2001; Obendorf, 2001).

Floor Sample Collection

All floor samples were obtained early in the morning between 5 a.m. and 7 a.m. before the activity for the unit had started for the day. The last room cleaning had occurred by 10 p.m. the night before. The investigator purposefully chose this time assuming there would be minimal disruption of any settled conidia.

The floor samples were taken from the same two locations in each patient room for 4 days. The locations were the first complete floor tile at threshold and below left corner of window. In each bathroom, the location selected was to the left of the commode.

Air Sample Collection

Due to the noise created by the air-sampling device, air samples were obtained each day from 9 a.m. to 5 p.m. according to patient schedules and family convenience. The locations for the air samples in the patient room were the first complete floor tile at threshold of the room facing into the room and beside the midline of the bed facing the head. One air sample was taken from the bathroom, midline, and facing inward.

Statistical Analysis

Analysis was accomplished with Statistical Analysis Software (SAS) and Microsoft Excel designed for Microsoft Windows environment desktop computing. The criterion for statistical significance was set at $\alpha = .05$.

The categories for statistical analysis were the following: sample category being air sample or floor sample; room side being the west, north, or east location of the patient room; room type described as a nonisolation or an isolation room; and room status being unoccupied or occupied during the 4 days of sample collection.

Before the statistical analysis, the air sample values were converted from CFU per 2 m$^3$ of air to CFU per 1 m$^3$ of air. This allowed for the comparison of the air sample results to the acceptable institutional air baseline standard that was established a few years ago. The satisfactory baseline established for the air is 8.1 cfu/m$^3$ of total fungus and 0.4 cfu/m$^3$ of Aspergillus. This baseline represents the average value of fungal conidia in the air at all locations in the patient care building from past air samples collected since 1995. These samples were random and collected from patient rooms, corridors, nursing stations, elevators, and stairwells (Dr. Jon McCullers, personal communication, October 8, 2002).

There has never been an acceptable institutional baseline level established for total fungus and Aspergillus for samples collected from the floor or from any other surfaces. Thus, no comparisons can be made between floor sample values of total fungus and Aspergillus and a floor standard baseline level for total fungus and Aspergillus.

Results

Research Question 1

What are the levels of total fungus and the levels of Aspergillus of air samples and floor samples obtained from patient rooms and bathrooms on a pediatric HSCT unit?

Sample sizes, sample means, sample standard deviations, minimum values, and maximum values of total fungus and Aspergillus for the air and the floor were determined for location and type of room (see Tables 1–4). Then the mean values were determined for sample category, room side, room type, and room status. After visual inspection of the results of the mean values in the air for location, day, sample category, room side, room type, and room status, it was determined that none of the mean values were above the acceptable, institutional baseline standard. This was further verified by $t$ tests.
Research Question 2

Are the levels of total fungus and *Aspergillus* obtained from the air samples less than or equal to the accepted institutional air baseline standard?

The *t* test for total fungus and *Aspergillus* in the air showed no statistically significant differences, *t* = −11.07, *p* > .99 for total fungus, and *t* = −9.54, *p* > .99 for *Aspergillus*, between the measured value and the standard air baseline value (see Table 5).

The *t* test for total fungus and *Aspergillus* in different room types in the air showed no statistically significant differences for nonisolation rooms, *t* = −24.09, *p* > .99 for total fungus and *t* = −9.20, *p* > .99 for *Aspergillus*, or for isolation rooms, *t* = −1.78, *p* = .837 for total fungus and *t* = −2.8, *p* = .891 for *Aspergillus*, between the measured value and the standard air baseline standard (see Table 5).

The *t* test for total fungus and *Aspergillus* for different room status in the air showed no statistically significant differences for unoccupied rooms, *t* = −8.02, *p* > .99 for total fungus and *t* = −2.61, *p* = .94 for *Aspergillus*, or for occupied rooms, *t* = −8.41, *p* > .99 for total fungus and *t* = −11.41, *p* > .99 for *Aspergillus* (see Table 7).

Research Question 3

Are there differences in total fungus and *Aspergillus* among sample category, location, day, room side, room type, and room status?

There was a significant difference in total fungus in the air for room type, *p* = .0029 (see Table 8). When referring to the mean values of total fungus for room type in the air, it is found that the total fungus levels are higher in the isolation rooms than in the nonisolation rooms. The mean total fungus level for the nonisolation rooms was 2.486. The mean level of total fungus for the isolation rooms was 5.500 (see Table 3). Therefore, the level of total fungus was higher in the isolation rooms than the nonisolation rooms.

There also was a significant difference in total fungus for location in the air, *p* = .0335 (see Table 8). When referring to the mean values of total fungus for location, it is found that the bathroom location air samples for total fungus were higher than the other two air sample locations in the patient room (see Table 1).

Last, there was a significant difference in total fungus on the floor among locations, *p* = .0197 (see Table 9). When referring to the mean values obtained for location (see Table 2), it is found that the floor location in the bathroom had smaller values than those of total fungus in the other two locations in the patient room.

Conclusions

Despite the stringent environmental controls adopted by the institution to protect the HSCT patient, environmental fungus and *Aspergillus* were detected. The prevalence and levels of total fungus and *Aspergillus*...
on a pediatric HSCT were determined. The results of the study indicated three areas of significant findings.

First, the levels of total fungus among room type in the air of the isolation rooms were higher than the total fungus found in the nonisolation rooms. It may be necessary for a maintenance inspection to be performed to ensure that the use of negative pressure, glass doors, and an anteroom has not interfered with the air flow efficiency in the isolation rooms. The air in the isolation rooms should be surveyed randomly, over a longer period of time, to see if the total fungus levels are consistently higher in the isolation rooms than in the nonisolation rooms. Also, longer periods of sample collection at random times may be more beneficial for detecting relationships among sample category, locations, days, room side, and room status. It may be useful to determine a standard baseline for the isolation rooms and the nonisolation rooms. It seems that because isolation rooms are used for patients who are carriers of a contagion that further complicates their immune status, the acceptable levels of total fungus and Aspergillus should at least be the same as in the nonisolation rooms if not deserving of an even lower standard air baseline.

Second, surveillance of the total fungus levels from the air in patient bathrooms should occur over a longer period of time because it was found that the total fungus levels among locations in the air were higher in the patient bathroom than in the air of the other two locations in the patient room. It may be beneficial to establish a standard baseline for the total fungus of air samples from patient bathrooms. The bathroom air supply is not hepafiltered a second time at point of entry (as it is in the patient room). Lack of a second hepa-

### Table 5. $t$ Test for Total Fungus and Aspergillus in the Air Compared With Baseline Values

<table>
<thead>
<tr>
<th>Fungus Type</th>
<th>Baseline Level</th>
<th>$M$</th>
<th>$t$</th>
<th>$p$ Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total fungus</td>
<td>8.1</td>
<td>3.034</td>
<td>-11.07</td>
<td>&gt;.99</td>
</tr>
<tr>
<td>Aspergillus</td>
<td>0.4</td>
<td>0.101</td>
<td>-9.54</td>
<td>&gt;.99</td>
</tr>
</tbody>
</table>

### Table 6. $t$ Test for Total Fungus and Aspergillus in Different Room Types in the Air

<table>
<thead>
<tr>
<th>Room Type</th>
<th>Fungus Type</th>
<th>df</th>
<th>$t$</th>
<th>$p$ Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Noncontagious</td>
<td>Total fungus</td>
<td>8</td>
<td>-24.09</td>
<td>&gt;.99</td>
</tr>
<tr>
<td>Noncontagious</td>
<td>Aspergillus</td>
<td>8</td>
<td>-9.20</td>
<td>&gt;.99</td>
</tr>
<tr>
<td>Contagious</td>
<td>Total fungus</td>
<td>1</td>
<td>-1.78</td>
<td>.837</td>
</tr>
<tr>
<td>Contagious</td>
<td>Aspergillus</td>
<td>1</td>
<td>-2.8</td>
<td>.891</td>
</tr>
</tbody>
</table>

### Table 7. $t$ Test for Total Fungus and Aspergillus in Different Room Status in the Air

<table>
<thead>
<tr>
<th>Room Type</th>
<th>Fungus Type</th>
<th>df</th>
<th>$t$</th>
<th>$p$ Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unoccupied</td>
<td>Total fungus</td>
<td>2</td>
<td>-8.02</td>
<td>&gt;.99</td>
</tr>
<tr>
<td>Unoccupied</td>
<td>Aspergillus</td>
<td>2</td>
<td>-2.61</td>
<td>.94</td>
</tr>
<tr>
<td>Occupied</td>
<td>Total fungus</td>
<td>7</td>
<td>-8.41</td>
<td>&gt;.99</td>
</tr>
<tr>
<td>Occupied</td>
<td>Aspergillus</td>
<td>7</td>
<td>-11.41</td>
<td>&gt;.99</td>
</tr>
</tbody>
</table>

### Table 8. Results of Analysis of Variance for Samples in the Air

<table>
<thead>
<tr>
<th>Classification</th>
<th>Fungus Type</th>
<th>$p$ Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Side (west, north, east)</td>
<td>Total fungus</td>
<td>.6058</td>
</tr>
<tr>
<td>Side (west, north, east)</td>
<td>Aspergillus</td>
<td>.7977</td>
</tr>
<tr>
<td>Room type (noncontagious, contagious)</td>
<td>Total fungus</td>
<td>.0029*</td>
</tr>
<tr>
<td>Room type (noncontagious, contagious)</td>
<td>Aspergillus</td>
<td>.3496</td>
</tr>
<tr>
<td>Room status (unoccupied, occupied)</td>
<td>Total fungus</td>
<td>.4519</td>
</tr>
<tr>
<td>Room status (unoccupied, occupied)</td>
<td>Aspergillus</td>
<td>.4884</td>
</tr>
<tr>
<td>Location (1, 2, 3)</td>
<td>Total fungus</td>
<td>.0335*</td>
</tr>
<tr>
<td>Location (1, 2, 3)</td>
<td>Aspergillus</td>
<td>.0824</td>
</tr>
<tr>
<td>Date (16, 17, 18, 19)</td>
<td>Total fungus</td>
<td>.4208</td>
</tr>
<tr>
<td>Date (16, 17, 18, 19)</td>
<td>Aspergillus</td>
<td>.3423</td>
</tr>
</tbody>
</table>

* $p < .05$.  

### Table 9. Results of Analysis of Variance for Samples on the Floor

<table>
<thead>
<tr>
<th>Classification</th>
<th>Fungus Type</th>
<th>$p$ Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Side (west, north, east)</td>
<td>Total fungus</td>
<td>.8420</td>
</tr>
<tr>
<td>Side (west, north, east)</td>
<td>Aspergillus</td>
<td>.4987</td>
</tr>
<tr>
<td>Room type (noncontagious, contagious)</td>
<td>Total fungus</td>
<td>.0870</td>
</tr>
<tr>
<td>Room type (noncontagious, contagious)</td>
<td>Aspergillus</td>
<td>.5317</td>
</tr>
<tr>
<td>Room status (unoccupied, occupied)</td>
<td>Total fungus</td>
<td>.4770</td>
</tr>
<tr>
<td>Room status (unoccupied, occupied)</td>
<td>Aspergillus</td>
<td>.1030</td>
</tr>
<tr>
<td>Location (1, 2, 3)</td>
<td>Total fungus</td>
<td>.0197*</td>
</tr>
<tr>
<td>Location (1, 2, 3)</td>
<td>Aspergillus</td>
<td>.1574</td>
</tr>
<tr>
<td>Date (16, 17, 18, 19)</td>
<td>Total fungus</td>
<td>.1683</td>
</tr>
<tr>
<td>Date (16, 17, 18, 19)</td>
<td>Aspergillus</td>
<td>.5063</td>
</tr>
</tbody>
</table>

* $p < .05$.
Fungus and *Aspergillus* on a Stem Cell Transplant Unit

The method of processing are also important. "The lack of condition of incubation (time and temperature), and sampling size. Other factors such as culture medium, and sampling (surfaces and/or air), frequency, location, collection of the sample from the threshold in the aerosolization of settled conidia (Anaissie et al., 2002; Graybill, 2001; Kullberg & Lashof, 2002; VandenBergh, Verweij, & Voss, 1999). It may not be effective or economically practical to provide this second hepafiltration in the patient bathroom. Therefore, to establish the need to provide point-of-entry hepafiltration in the patient bathroom, additional samples over time should be collected to show that consistently high total fungus levels are present. It seemed better that the levels of total fungus in the other two locations in the patient room were lower because the patient spends more time in the patient room than in the bathroom.

The last finding involved a significant difference between locations on the floor and amount of fungus. The bathroom floor sample location had less total fungus than the floor samples from the other two locations in the patient room. The attitude of the bathroom being a "dirty" place may promote a more thorough cleaning procedure to be applied in the bathroom by environmental services personnel. The threshold floor location may have higher total fungus counts than what is shown. The door to the patient room opens inward. The air current produced may have caused some aerosolization of settled conidia to occur prior to the collection of the sample from the threshold in the patient room. It may be beneficial for surveillance efforts to include the establishment of standard surface or floor baselines for locations in the patient room and bathroom. Floor sample and surface sample results can detect minor contamination and can serve as a good marker for lack of cleaning or filtration (Faure et al., 2002).

There are few standards for surveillance of nosocomial fungal presence in hospitals. It is difficult not only to compare findings institutionally but also to compare findings across studies because of the lack of a universal definition of IA, a lack of agreement on extent of disease, and the lack of widely recognized surveillance protocols. The lack of unstandardized methodology implies that the frequency of fungal isolation depends on a great number of factors. These include type of sampling (surfaces and/or air), frequency, location, and sampling size. Other factors such as culture medium, condition of incubation (time and temperature), and method of processing are also important. "The lack of standardized protocols and reference values for fungal environmental surveillance impairs comparison between studies" (Faure et al., 2002, p. 5).

These reference values should be standard baseline levels established for air, floor, and surface samples to ascertain the optimal acceptable levels for total fungus and *Aspergillus* on the HSCT unit. There are often no data on the baseline concentrations of total fungus and *Aspergillus*, and this makes it difficult to determine if an infection is associated with higher levels of total fungus in the hospital setting (Hajjeh & Warnock, 2001).

The results showed there were no levels of total fungus and *Aspergillus* in the air that was greater than the institution’s standard baseline for acceptable air levels. These acceptable standard baseline levels were determined from air samples taken from patient rooms, bathrooms, and common areas such as hallways and nurses’ stations. It would seem that comparison findings would be more reliable if weighed against institutional criteria established from the mean values of samples collected only from the HSCT unit. It has not been determined if the acceptable standard baseline levels of total fungus and *Aspergillus* on the HSCT unit should be made more strict and therefore lower than the other areas of the hospital because of the profound immunosuppression induced by HSCT.

It is expected that the air and floor values for total fungus and *Aspergillus* should be lower in the patient rooms than in the common areas of the hospital. The air to the patient room is hepafiltered twice, whereas the air to the common areas is hepafiltered once. There is less activity and fewer people in the room, thereby decreasing the disruption and subsequent aerosolization of settled conidia. It needs to be determined if the single hepafiltration in the patient bathroom and common areas of the hospital contribute to the higher total fungus and *Aspergillus* levels in the air, thereby increasing exposure to environmental contaminants.

For meaningful comparisons to be made, standard baseline levels should be established for air, floor, and surface samples collected from the HSCT unit alone. These standard baselines should provide acceptable levels for the locations of patient room, bathroom, and common areas. Then, evaluation of the HSCT environment can be based on consistent collection procedures and sampling routines.

In summary, the possibility of complete eradication of total fungus and *Aspergillus* from the hospital environment is questionable, and this expectation may be
unrealistic. The most effective and extant control measures for prevention of fungal exposure and transmission have been implemented on this HSCT unit. Routine standard collection methodology should be established for random air, floor, and surface sampling for total fungus and Aspergillus on the HSCT unit. The levels obtained should then be used to establish standard institutional baselines for acceptable levels of total fungus and Aspergillus on the HSCT unit. Deviation from these baselines can alert to increased levels of total fungus and Aspergillus, and initiation of appropriate corrective measures can be determined. Certainly, protective measures and surveillance of the hospital setting have an important role to play in the prevention of exposure to fungi and Aspergillus.

Increasing incidence of IA is evident after recovery of neutropenia and discharge from the protection of the hospital environment. Control of the outside environment obviously presents obstacles to effective control of environmental sources of fungus. Exploration into other areas that show potential efficacy in the diagnosis and treatment of fungal infection should be investigated.

Limitations

The 4-day sample collection was brief. This sample size was determined by capacity of the mycology laboratory to analyze the number of samples that were needed. Furthermore, the biostatisticians indicated that the number of samples collected over this 4-day period would suffice to represent the levels of total fungus and Aspergillus on the unit.

The reaction of the institution’s Environmental Services Department to the obvious sample collection on the unit could have been to apply more stringent cleaning to the patient rooms and bathrooms over this 4-day period. The department may have been concerned that the findings from this study could be used to evaluate cleaning practices on the unit.

Future Direction

Most cases of IA are infrequent and occur sporadically. It is unknown whether some cases of IA are hospital or community acquired. The minimal acceptable level of conidial density exposure has not been established; therefore, it is unknown how much exposure causes disease. Varying degrees of immunosuppression among patients affects the incubation period of Aspergillus as well as the time of exposure to initial symptoms. There is evidence that shows that Aspergillus has the propensity to reactivate in the setting of prolonged or recurring immunosuppression (Kontoyiannis & Bodey, 2002).

Treatment for IA is suboptimal without optimistic, convincing assurances for positive outcomes. The overall CFR reported by Lin et al. (2001) was 58%, and the CFR was highest for HSCT recipients (86.7%). Oftentimes, signs of infection do not occur until dissemination of disease is present. In a hospital-based survey of aspergillosis, Perfect et al. (2001) reported that despite receiving treatment with amphotericin B, more than half of the patients with IA do not survive more than 3 months.

It seems that the treatment of existing infection is a late intervention. It would be better to initiate measures before evidence of fulminating infection, when the chances of survival are greatest. The development of the new tests for the detection of circulating fungal cell wall antigens such as galactomannan and (1-3)-beta-D-glucan and the detection of fungal DNA by polymerase chain reaction (PCR) assay should be perfected. According to Ellis (2001), “Sensitivities and specificities for Aspergillus diagnosis are among the highest when a combination of galactomannan sandwich ELISA [enzyme-linked immunosorbent assay] and PCR is used” (p. 950). The significance of galactomannan and PCR at different stages of fungal burden and infection and their usefulness for guiding therapy should be examined.

Prophylaxis with antifungal agents may be warranted in the HSCT setting due to the increased risk of infection and poor outcomes following treatment. Studies should be done to investigate the maximum tolerated doses to be used for prophylaxis and for treatment so that toxicities can be minimized. The use of combination drug therapy should be investigated for the use of antifungal agents as synergists in their attack against fungal infection. Drug-resistant fungal organisms are being identified, and this has increased concern about the inadequacy of the present treatment available. Aspergillus infection is associated with a high mortality rate, but infection with a drug-resistant organism is almost always fatal.
Further investigation into the use of cytokines such as colony-stimulating factors and interferon to decrease the duration and effects of immune deficiencies should be continued (Ellis, 2001). If reconstitution of the hematopoietic system occurs with subsequent immunorestitution, the chances of acquisition of opportunistic fungal infection will be decreased.

**Implications for Nursing Practice**

It seems that diagnosis with invasive fungal disease evokes the same feelings of pessimism in nurses as it did 20 years ago. Treatment outcomes and prognosis remain poor. Nurses who care for pediatric HSCT patients with fungal infections are witnesses to the suffering that accompanies this illness. Also, the nurses’ workload increases due to fungal infections and care of these high acuity patients. Nurses must understand that immunosuppression, opportunistic pathogens, and the hospital environment are contributory factors to the acquisition of invasive fungal infection. Nursing responsibilities in the care of the HSCT patient include delivery of physical care, provision of education regarding infection, enforcement of infection control guidelines and policies, recognition of the clinical signs of fungal infection, and contribution to the research regarding prevention of fungal infection.

**References**


Richardson, M. D., Rennie, S., Marshall, I., Morgan, M. G., Murphy, J. A., Shankland, G. S., et al. (2000). Fungal surveillance...


Pain is a frequent complication of subcutaneous cytokine injections in children. A randomized crossover trial was conducted to determine the least painful and preferred method of cytokine administration for children and young people. The current standard practice of subcutaneous injection was compared with the use of Insuflon (Maersk Medical, Roskilde, Denmark), a subcutaneous indwelling catheter. Children aged between 1 month and 18 years undergoing treatment within the oncology/hematology unit of a single tertiary hospital and receiving cytokines were eligible for the study. Twenty children participated in the study, each child receiving both administration methods in random order during sequential cytokine treatment courses. There was a trend toward higher pain scores when using subcutaneous injections for drug administration compared to Insuflon. Seventy-five percent (n = 15) of the children who completed the trial and their families preferred using Insuflon for subcutaneous drug administration. Consideration needs to be given, however, to those who refused to enter the study, withdrew, or continued because of a preference for subcutaneous injections. Current practice at the Women’s and Children’s Hospital is to allow the child and parents to choose their preferred treatment modality for subcutaneous drug administration.

Key words: child, injection, Insuflon, oncology/hematology, subcutaneous

Subcutaneous injections have been recognized as a common cause of distress in pediatric patients living with a chronic illness (Hanas, 2001). Painful injections can lead to changed behavior, difficulty administering subcutaneous medications, and to deterioration in the therapeutic relationship between the patient and nurse. Children undergoing chemotherapy for malignancies often require subcutaneous injections as part of their treatment plan. Granulocyte-colony stimulating factor (G-CSF) is a cytokine routinely given to pediatric oncology patients following chemotherapy to ameliorate neutropenia and to reduce the risk of infection. The anecdotal experience of oncology nurses within this unit has suggested that pediatric patients undergoing daily G-CSF administration as well as their carers suffer discomfort and distress.

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flon is a Teflon subcutaneous catheter, which can remain in situ for 7 days. It has been shown to reduce the pain of repeated injections in both diabetic (children with insulin-dependent diabetes) (Hanas & Ludvigsson, 1989; Long & Hughes, 1991) and nondiabetic populations (pregnant women requiring twice-daily heparin) (Anderson et al., 1993). The manufacturers of Insuflon caution its use in immunosuppressed or leukopenic patients due to a potential for increased risk of infection (Pharma-Plast International A/S, 1993). However, anecdotal and observational data in pediatric oncology patients suggest Insuflon is associated with minimal adverse outcomes and may increase patient comfort and compliance (V. Marizinotto, personal communication, February 1999).

There are currently no randomized controlled trials evaluating the use of an indwelling subcutaneous cannula (Insuflon) in the pediatric oncology/hematology population. This study aims to quantify and describe patient experience by a randomized crossover trial of G-CSF administration. The reporting of this study follows the consolidated standard of reporting trials guidelines (Altman et al., 2001).

**Method**

**Participants**

All children requiring at least two cycles of G-CSF treatment in the Department of Clinical Hematology/Oncology at the Women’s and Children’s Hospital (WCH), in Adelaide, Australia, who were between 1 month and 18 years of age were eligible for the study. Current patients and newly diagnosed patients who were being treated for a range of malignancies including leukemia, lymphoma, and solid tumors were included. The consultant oncologists (including BS) or the research nurse (SD or BM) recruited participants from the inpatient and outpatient clinic. Parental written informed consent, and where possible patient assent, was obtained for all participants. Ethics approval was granted by the WCH and the Royal District Nursing Service ethics committees.

**Randomization**

Participants were randomly allocated to receive G-CSF using either Insuflon or subcutaneous injections. The second cycle was administered using the alternate method. The drug used in both treatments was Filgastrim (Amgen, Thousand Oaks, CA). The randomization schedule was computer generated and sealed in opaque envelopes in sequential order by a researcher not involved in recruitment or in the delivery of patient care (CC). Treatment allocation was obtained by telephoning a separate ward in the hospital where the next envelope was opened and treatment order assigned. This was documented in a prominent place in the case notes.

**Interventions**

Standard subcutaneous injections using a 25-gauge needle were administered after the application of EMLA (Astra Pharmaceuticals) or AnGel (amethocaine 4% hospital formula) anesthetic cream to the thigh. Rotation between the thighs occurred systematically. The Insuflon was inserted into the posterior aspect of the arm and secured as directed by the manufacturer after the application of either Emla or AnGel anesthetic cream.

A registered nurse in the hospital or a community nurse in the child’s home administered G-CSF for 7 days for both study arms. A 27-gauge needle was used for Insuflon injections. The dead space of the Insuflon is 0.0075 ml, and therefore the device does not require flushing between drugs unless this volume represents 10% or more of the required dose. All nurses involved in the study were instructed on the study protocol and method of drug administration for both arms of the study including the use of pain assessment tools. The G-CSF was administered over 30 seconds for both standard and Insuflon subcutaneous injection; pain assessment occurred immediately after.

**Instruments**

The Modified Behavioral Pain Scale (MBPS) is a revised behavioral scale validated for use in children younger than 7 years and is based on the Children’s Hospital of Eastern Ontario Pain Scale (Taddio, Nulman, Goldbach, Ipp, & Koren, 1994). This pain scale was specifically developed for use with injection pain and involves scoring the children on three behavioral states: facial expression, cry, and movements. The total score for this scale ranges from 0 to 10 depending on the
child’s observed behavior. Taddio et al. (1994) reported that the correlation of the MBPS scores to the visual analogue scale (VAS) scores in their study yielded a Spearman correlation coefficient of .608 ($p < .001$), suggesting that both scales measured similar responses.

The scales used for children aged 7 years and older include the colored analogue scale (CAS) and facial affective scale (FAS), which are versions of Vass (McGrath et al., 1996). These scales are suitable for rating pain during procedures for children aged 6 years and older (Hanas, 2001) and have been recommended for use in research (Champion, Goodenough, von Baeyer, & Thomas, 1998). The FAS measures the unpleasantness of pain, and the numerical values represent the magnitude of pain from a child’s perspective, with scores ranging from 0 to 1. The CAS measures the strength of a child’s pain, and scores range from 0 to 10.

The injection sites were observed and recorded daily by nursing staff prior to administration of G-CSF for evidence of local bruising, local infection, swelling, and potency of the Insuflon. A record of febrile episodes experienced during the neutropenia phase was collected routinely for both treatment arms.

The parent-child and nurse questionnaires were designed specifically for this project by the research team and were piloted: minimal changes were required. Both parent-child and nurse questionnaires were administered at the end of the two treatment cycles to determine preference for treatment modality. The parent-child questionnaire consisted of a straight preference question, “Which method of receiving G-CSF would you (or your child) choose to use in the future?” and seven open-ended questions prompting the respondents regarding the comfort of Insuflon using a 4-point Liker-type scale with 1 = never, 2 = sometimes, 3 = frequently, and 4 = always. There was one question soliciting any comments. The nurses’ questionnaire had four questions that asked how much pain the nurse felt the child experienced with each method, which method they felt was more distressing for the child, and whether the nurse had a preference for either method.

Hypothesis

It was hypothesized that children receiving G-CSF via Insuflon would have reduced pain scores compared with those receiving a daily subcutaneous injection. The primary study endpoints were the pain score for each method and the patient’s (or parents’) preference. Secondary endpoints included local side effects (bruising, local inflammation, skin integrity), febrile episodes, and staff preference for standard subcutaneous injection or Insuflon.

Sample Size

Using variance estimates reported in the literature (McGrath et al., 1996), a sample size of 40 was determined to detect a 3-point reduction in pain score (80% power and $p < .05$). Given that approximately 50 children are newly diagnosed per year in addition to current eligible patients, it was anticipated that the trial would be complete within 12 months. Analysis was undertaken by intention to treat.

Data Analysis

Due to unanticipated recruitment difficulties (lower than expected patient numbers and higher than expected patient refusals), the study was terminated after 20 participants had been recruited. Because of this, a nonparametric analysis was undertaken. In a nonparametric treatment of pain scores, each child’s mean pain score was treated as showing either a decrease when using Insuflon or an increase. Under the null hypothesis (mode of administration of G-CSF had no systematic effect on pain score), the probability of an increase (or decrease) is .5, and the significance of each result was calculated as the sum of the appropriate binomial probabilities.

Results

Participant Flow

Twenty participants were recruited into the study, with 15 participants completing each intervention (see Figure 1). The study was conducted between April 1998 and September 2000. One third of eligible patients chose not to participate ($n = 11$). The most common reason for not participating was a preference for subcutaneous injections ($n = 6, 54\%$). Three patients (27%) chose not to participate because they had previously used Insuflon and wanted to continue with this treatment modality. Five participants withdrew from the trial.
after only completing one arm of the study, 2 because they preferred subcutaneous injections, and 3 because they preferred Insuflon. Table 1 outlines the clinical characteristics of each group. Comparable proportions for both arms had used G-CSF and Insuflon before the trial. There were more children younger than 7 years who were randomized to Insuflon for their first treatment cycle.

### Pain Scores

The summary statistics for the pain scores for each age group are shown in Tables 2 through 4. More participants (8 vs. 3) recorded an increase in pain score on the CAS when using subcutaneous injection compared to Insuflon, but this was not statistically significant \( (p = .11) \) (see Table 5). There was little suggestion of any difference on the MBPS score or FAS score.

### Patient/Parent Preferences

Patient preference for Insuflon following a collation of the questionnaires was 75% \( (n = 15) \), and patient preference for standard subcutaneous injection was 25% \( (n = 5) \) (see Table 6). Under the null hypothesis that children have no preference for Insuflon over subcutaneous injection, the probability of 5 or fewer of 20 children preferring subcutaneous injections would be .02, which is statistically and clinically significant.

Six of the 7 children younger than 7 preferred Insuflon to subcutaneous injections, as did 9 of the 13 children aged 7 to 18. Parents and children were given the opportunity to comment in the questionnaire about their experience of using Insuflon. The comments were generally positive as these quotes show: “a very pain free way of administering the drug”; “much easier than
injections. Less or no stress or pain for child”; “doesn’t hurt as much . . . doesn’t get as anxious.”

Five children (4 of whom were 7 to 18 years of age) preferred subcutaneous injections. The older children who chose subcutaneous injections recorded the following reasons: “there is not a constant reminder of having to have injections,” “not wanting another thing sticking out of the body,” and “prefers to have injections so that they are out of the way.”

Nursing Preferences

Fifty-five questionnaires were distributed to community and hospital nursing staff with a response rate of 47% (n = 26). Eighty-five percent (n = 22) of the nurses indicated that the subcutaneous injection method caused the greatest distress in children, and the same percentage of nurses preferred to administer cytokines using the Insufion method. Eight percent (n = 2) of the nurses preferred to use subcutaneous injections, and 8% (n = 2) had no preference for either method (see Table 6).

Skin Assessments

The skin was observed daily for redness, bruising, and swelling and scored as 0 if no reaction, 1 if the area measured between 3 and 10 mm, and 2 if between 10 and 20 mm (see Table 7). A total of 235 observations were made, 127 for Insufion and 108 for subcutaneous injections. No redness or bruising was observed with the Insufion, and minimal redness and bruising occurred with subcutaneous injections (redness: n = 3, 3%; bruising: n = 25, 23%). Tenderness was also observed and recorded daily as either “yes” or “no.” The prevalence of tenderness was minimal for both groups (Insufion: n = 6, 5%; subcutaneous injection: n = 5, 5%), and there was a similar distribution of febrile neutrogea episodes in both treatment arms (Insufion: n = 7, 35%; subcutaneous injection: n = 8, 40%). Three participants required the Insufion to be resisted due to leakage and fixation problems during the trial.

Comfort

Participants (or their family) were asked to assess the level of comfort experienced when using the indwelling subcutaneous cannula by answering eight questions using a 4-point Type-type scale in the parent-child survey. The majority of respondents found the Insuflon never or sometimes caused inconvenience or discomfort (see Table 8). One respondent found that the Insuflon always affected their daily living activities, and 1 respondent found that it frequently caused itching.

Cost

Although not a focus of the study, costing for both methods of administration for a 7-day treatment (including all supplies necessary for administration) is AU$11.22 for Insuflon and AU$23.80 for standard subcutaneous injections using the EMLA cream. The increased cost of using standard subcutaneous injections

<table>
<thead>
<tr>
<th>Table 2. Mean Pain Scores 7 to 18 Years: Colored Analogue Scale</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
<tr>
<td>-------------------</td>
</tr>
<tr>
<td>Response rate</td>
</tr>
<tr>
<td>Mean</td>
</tr>
<tr>
<td>Standard deviation</td>
</tr>
<tr>
<td>Median</td>
</tr>
<tr>
<td>Range</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Table 3. Mean Pain Scores 7 to 18 Years: Facial Affective Scale</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
<tr>
<td>-------------------</td>
</tr>
<tr>
<td>Response rate</td>
</tr>
<tr>
<td>Mean</td>
</tr>
<tr>
<td>Standard deviation</td>
</tr>
<tr>
<td>Median</td>
</tr>
<tr>
<td>Range</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Table 4. Modified Behavioral Pain Scale Score for Children Younger Than 7 Years</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
<tr>
<td>-------------------</td>
</tr>
<tr>
<td>Response rate</td>
</tr>
<tr>
<td>Mean</td>
</tr>
<tr>
<td>Standard deviation</td>
</tr>
<tr>
<td>Median</td>
</tr>
<tr>
<td>Range</td>
</tr>
</tbody>
</table>
Table 5. Direction of Mean Pain Score Change With Standard Subcutaneous Injection Compared to Insuflon

<table>
<thead>
<tr>
<th></th>
<th>Facial Affective Scale (n = 13)</th>
<th>Colored Analogue Scale (n = 13)</th>
<th>Modified Behavioral Pain Scale (n = 7)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number with increase score</td>
<td>5</td>
<td>8</td>
<td>3</td>
</tr>
<tr>
<td>Number with decrease score</td>
<td>5</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Missing data (n)</td>
<td>3</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>p valuea</td>
<td>.62</td>
<td>.11</td>
<td>.5</td>
</tr>
</tbody>
</table>

a. Assuming binomial outcomes with probability .5 as described in the text.

Table 6. Parent/Child and Nurse Preference for Insuflon or Standard Subcutaneous Injection

<table>
<thead>
<tr>
<th></th>
<th>Insuflon</th>
<th>Standard Subcutaneous Injection</th>
<th>No Preference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parent/child preference</td>
<td>15  75</td>
<td>5     25</td>
<td>0</td>
</tr>
<tr>
<td>Nurse preferencea</td>
<td>22   85</td>
<td>2     8</td>
<td>2            8</td>
</tr>
</tbody>
</table>

a. Percentages do not sum to 100 due to rounding.

Table 7. Skin Assessment

<table>
<thead>
<tr>
<th></th>
<th>Insuflon Score (n = 127 Observations)</th>
<th>Standard Subcutaneous Injection Score (n = 108 Observations)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Redness</td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>Bruising</td>
<td>127</td>
<td>100</td>
</tr>
<tr>
<td></td>
<td>83</td>
<td>77</td>
</tr>
</tbody>
</table>

NOTE: Score: 0 = no reaction; 1 = area 3 to 10 mm; 2 = area 10 to 20 mm.

Table 8. Comfort of Insuflon

<table>
<thead>
<tr>
<th>Question (Response Rate, n = 20)</th>
<th>Never</th>
<th>Sometimes</th>
<th>Frequently</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td></td>
<td>n</td>
<td>%</td>
<td>n</td>
<td>%</td>
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<tr>
<td></td>
<td>n</td>
<td>%</td>
<td>n</td>
<td>%</td>
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<td></td>
<td>n</td>
<td>%</td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td></td>
<td>n</td>
<td>%</td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td></td>
<td>n</td>
<td>%</td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>Inconvenient in upper arm (n = 17, 85%)</td>
<td>17</td>
<td>47</td>
<td>9</td>
<td>53</td>
</tr>
<tr>
<td>Caught on clothing (n = 18, 90%)</td>
<td>12</td>
<td>67</td>
<td>6</td>
<td>33</td>
</tr>
<tr>
<td>Caused itching (n = 19, 95%)</td>
<td>11</td>
<td>58</td>
<td>7</td>
<td>37</td>
</tr>
<tr>
<td>Scarred/markd where inserted (n = 19, 95%)</td>
<td>16</td>
<td>84</td>
<td>3</td>
<td>16</td>
</tr>
<tr>
<td>Local skin reaction (n = 19, 95%)</td>
<td>17</td>
<td>89</td>
<td>2</td>
<td>11</td>
</tr>
<tr>
<td>Foam pad or covering fell off during treatment period (n = 18, 90%)</td>
<td>15</td>
<td>83</td>
<td>3</td>
<td>17</td>
</tr>
<tr>
<td>Wings of Insuflon caused irritation (n = 19, 95%)</td>
<td>17</td>
<td>89</td>
<td>2</td>
<td>11</td>
</tr>
<tr>
<td>Affected daily living activities (e.g., swimming, bathing, playing sports) (n = 18, 90%)</td>
<td>13</td>
<td>72</td>
<td>4</td>
<td>22</td>
</tr>
</tbody>
</table>
is largely attributable to the daily use of EMLA anesthetic cream. When the cost of each method is assessed using hospital-produced AnGel cream (AUS$8.35 for Insuflon and AUS$3.72 for standard subcutaneous injections), the cost is less for standard subcutaneous injections.

**Discussion**

Reducing pain and discomfort associated with injections in the pediatric patient population is an ongoing challenge for health professionals. This study demonstrated a strong preference for Insuflon by patients and parents, indicating that these groups perceive Insuflon to reduce anxiety and discomfort associated with subcutaneous drug administration in the pediatric hematology/oncology patient population.

Previous studies using Insuflon have indicated increased compliance and decreased pain with subcutaneous medication in both adults (pregnant women requiring twice-daily heparin) and children with insulin-dependent diabetes (Anderson et al., 1993; Hanas & Ludvigsson, 1989; Long & Hughes, 1991). The results presented here show that there was decreased local reaction with Insuflon and no difference in febrile episodes when compared to standard subcutaneous injections. Pegoli (1997) studied 280 injections of G-CSF administration via indwelling subcutaneous cannula in adult hematology/oncology patients without any evidence of local infection, and Hanas (2001) did not observe any major infections in association with Insuflon use in a nonimmunocompromised population. Lamacraft, Cooper, and Cavalletto (1997) assessed the use of an indwelling subcutaneous cannula technique for morphine administration in children and found it caused minimal distress, had no major complications, and nursing staff preferred this technique. Nursing staff in the current study also indicated that patient distress was decreased when using Insuflon compared with standard subcutaneous injection and that this was their preferred mode of drug administration.

Although the majority of participants preferred the Insuflon, others preferred standard subcutaneous injections. The majority of eligible patients who chose not to participate in the trial did so because of their already established preference for standard subcutaneous injections. In addition, 2 participants older than the age of 7 years who were randomized to subcutaneous injections withdrew because of their preference for standard subcutaneous injections. A preference against Insuflon has previously been reported when children older than 10 years chose to stop Insuflon (Hanas, 2001). The current study shows a similar trend. Younger children displayed a stronger preference for Insuflon than did older children. It is clear from the current study and the results found by Hanas (2001) that with increasing age, the individual’s personal choice is influenced by factors other than pain and comfort alone, and these include a desire not to have visible reminders of their disease. For some older children, subcutaneous injections will be their preferred option.

This study demonstrates a strong preference for Insuflon in this pediatric hematology/oncology patient population. No adverse events were noted; however, the sample size was not large enough to make any firm conclusions regarding safety. We recommend that all children receiving cytokines should be offered the option of using Insuflon or subcutaneous injections.

**Acknowledgments**

Thank you to the children and families who participated in the trial and also to the following for their ongoing support during the study: Maeve Downe, Adrienne Stoddart, Jill Schroeder, Kim Ingham, Royal District Nursing Society Nurses, Country Community Nurses, Suzie Kambuts, and the nursing staff of Brookman Ward and Ronald McDonald Children’s Clinic. The South Australian Bluey Day Foundation kindly funded this study.

**References**


The objective of this study is to identify common problems and helpful resources important to parents of children with brain tumors by illness phase and to determine associations with stress. Parents with a child diagnosed within the past 10 years were surveyed regarding healthcare provider interactions, medical information/education, health care utilization and psychosocial concerns. Survey items were rated as problems or helpful, and for importance at each phase of illness. Stress was recorded from 0 to 10 for each phase; associations with demographic characteristics and items were tested statistically. A total of 139 parents from 87 families responded, with 45 mother-father pairs. Half reported unmet informational needs as most important during diagnosis (etiology), recurrence (complementary therapy), end of life (dying process), and remission (long-term effects). Mothers experienced greater stress than fathers during adjuvant treatment ($p = .009$). Stress increased ($p < .05$) during diagnosis and hospitalization/surgery with being married, at hospital discharge because of changes in child’s personality/moods, during adjuvant treatment with unmet informational needs regarding stopping treatment, during recurrence regarding employment concerns, and during remission with unmet informational needs regarding life-time expectations. Stressors changed across phases of illness. Married respondents appeared at increased risk for stress. Further work is needed to tailor and evaluate interventions to decrease stress during illness phases.

Key words: pediatrics, neurooncology, stress, resources, family, marital status

Brain tumors are the second most common neoplasm and the most common solid tumor in children, with central nervous system (CNS) tumors composing 20% of those with cancer (Bleyer, 1990; National Institutes of Health, National Cancer Institute, 1998; Shiminski-Maher, Abbott, Wisoff, & Epstein, 1991). Although the medical effects of CNS tumors in children have been studied extensively (Ertel, 1980; Kennedy & Leyland, 1999; McAllister et al., 1997; Roman & Sperduto, 1995; Siffert, Greenleaf, Mannis, & Allen, 1999), little is known about how the illness affects the family (Binger et al., 1969; Masera et al., 1999; Wolfe et al., 2000). With advances in treatment of these tumors over the past 20 years, improvement in survival may not correspond with how well the family’s needs are being met. Symptoms associated with aggressive treatment, sequelae of CNS tumors, as well as the diagnosis itself can have a devastating impact on the child and family. A smaller family network has been implicated in increasing the risk of morbidity and mortality (Cohen & Symes, 1985); however, this and other stressors present over the course of this disease have not been studied adequately. With the integration of family-centered care into the health care environment, no evidence-based guidelines exist for redirecting resources to best meet the needs of these families in providing...
teaching, support, and involvement of family members during care (Langton, 2000).

Noninvasive neuroimaging has made the diagnosis of pediatric CNS tumors fairly straightforward. Surgery is usually aimed at gross total resection of tumor and histologic confirmation of tumor type (Benk et al., 1999; Packer, 1999; Pollack, 1999). Chemotherapy and radiation are frequently used adjunct treatments. Family-centered care including examination of the child’s development and parental and sibling concerns are often of secondary importance to the medical team during this period (Sahler, Frager, Levetown, Cohn, & Lipson, 2000). Lazarus and Folkman (1984) suggested that when an individual has determined that a threat (i.e., diagnosis) exists, a response is made using one of two strategies: emotion focused, utilizing psychological defense mechanisms, or problem focused, in which the individual acquires information, new skills, and/or behavioral responses. However, Shapiro (1983) recognized that coping resources, including family and social contacts, can have either a positive or a negative effect on the individual.

The current research is motivated by how best to tailor resources to meet the needs of these families. Family concerns formed the foundation for the two objectives for this needs assessment study: to identify the most commonly reported problems and resources perceived as important by parents during each phase of the health care continuum (diagnosis, hospitalization/surgery, hospital discharge, adjuvant treatment, recurrence, and remission or end of life) and to determine whether these factors as well as family demographic characteristics were associated with stress. Our hypothesis is that a smaller family network (i.e., single-parent family) is a significant risk factor for increased stress.

Materials and Methods

Subjects

A regional survey of parents/guardians of children with the diagnosis of a brain or spinal cord tumor was conducted during 1999 and 2000. Families were included if they had a child diagnosed with a brain or spinal cord tumor within the past 10 years and had received care or lived in the northeastern region of the United States. Participants were recruited from community resource organizations, medical centers with large pediatric neurosurgery departments, brain tumor associations and foundations, local advocacy and support groups, newsletters, Web sites, and listservers. Investigators contacted an administrator or clinician from each recruitment source to discuss the purpose of the study. Interested groups received copies of a letter that they forwarded to patients’ families. The letter stated the purpose of the study and eligibility and requested that minimal demographic and contact information be returned to investigators in enclosed envelopes. This procedure ensured anonymity of families choosing not to participate. Upon receipt of the contact information, surveys were then mailed to families with postage-paid return envelopes. The study was approved by Montefiore Medical Center’s Institutional Review Board for the Protection of Human Subjects.

Survey Instruments

An instrument was designed to represent the scope of health care, educational, and psychosocial concerns that may be present at each phase of illness. The scope of items reflects concerns identified through qualitative analysis of transcripts from parent focus group interviews conducted the prior year (Freeman, O’Dell, & Meola, 2000, 2001). The instrument was not used to score the degree of needs. Rather, the association between each item on the instrument and the degree of stress was evaluated statistically. To help validate the instrument with regard to content validity, items were reviewed by a multidisciplinary expert panel, which was composed of a pediatric neurologist, pediatric radiation oncologist, pediatric neurosurgeon, clinical nurse specialists, social workers, and educators. Each member of the panel reviewed the verbiage of the item and included additional items according to his or her own experience. In addition, drafts of the instrument were critiqued by parents not participating in the survey; these parents indicated that survey completion time would likely range between 30 and 45 minutes. The surveys encompassed four general content areas: interactions with health care providers, medical information and education, health care delivery/utilization, and psychosocial issues. Items included the manner and availability of health care providers, use of the Internet, time for decision making, religious concerns, insurance issues and entitlements, employment, mental
health services, home and child care, social support, treatment of pain, hospital visitation policies, non-medical charges, changes in personality/moods and appearance, educational resources, and information about etiology, treatment options, and prognosis. For end of life, additional items included emotional preparation for the death, information regarding the dying process, and provision of physical and emotional support.

Figure 1 illustrates the format of the questionnaire. Each item on the survey instrument was to be rated as helpful or as a problem, and for its level of importance. To ensure further that the scope of items was valid, respondents were provided space at each phase of illness to include additional items. The level of stress was requested for each phase of illness and was coded from 0 to 10, with 10 = extremely stressed. Demographic information was requested separately.

### Definitions for Analyses

Both mothers and fathers were eligible to complete survey instruments. Because responses from individuals from the same family are not independent, a summary unit of analysis was defined to represent the “family” response. For families with one parent responding, the family response was that of the respondent. For families with responses from both mothers and fathers, if either parent indicated the item to be helpful, then the family response was “helpful.” The same coding was used for “problem.” For importance responses (not, slightly, very important), the greater level of importance of the two parents was considered the family response. To support results from the family analysis, analyses were also performed using responses from individuals. In addition, for the subset of families with responses from both parents (mother-father pairs), parent responses were compared, evaluating the legitimacy of family summary responses.

Important problems and helpful resources were those rated by parents as very important. However, if an item was identified as a problem, and regardless of whether the problem was identified as either slightly or very important, the problem was considered as an important problem by investigators. This method allowed investigators to focus on all problems as well as very important helpful resources.

### Statistical Methods

For each phase of illness, relative frequencies for important problems and important helpful resources were derived. The relative frequency distributions of slightly and very important responses were also examined. Associations between stress and each item’s “helpful” and “problem” response were assessed using Wilcoxon rank sum tests. Associations between categorical demographic characteristics and stress were assessed using Kruskal-Wallis tests and for continuous variables, Spearman rank correlations. Items or characteristics with significant associations with stress (p < .05) and with relative frequencies of 33% or greater for problems, 67% or less for helpful resources, or correlations with magnitudes of .25 or greater were candidates for deriving the final multiple logistic regression models using a forward stepwise procedure. Differences between mother-father pairs were assessed for significance using Wilcoxon signed rank tests. For
all analyses, \( p \) values less than .05 were considered significant. No data-inputting methods were used for missing data. All analyses were performed using SAS Version 8, Cary, NC.

**Results**

A total of 268 families provided contact information indicating their willingness to participate in the survey. Of these, 87 families (32.5%), representing 139 parents/guardians and 48 mother-father pairs, responded to at least the diagnosis phase of the survey. More subjects responded to the diagnosis phase than any other. Among the 87 families, there were 78 mothers (mean age = 42 years, \( SD = 7.2 \)) and 54 fathers (mean age = 44 years, \( SD = 9.5 \)). In 48 families, both mothers and fathers completed surveys. Of the remaining 39 families, 3 of 9 fathers were married, 2 were divorced, and 4 had unknown marital status; 18 of 30 mothers were married, 11 were divorced, and 1 had unknown marital status. The average time from diagnosis to time of completion of the survey instrument was 4.6 years (\( SD = 2.6 \)). At time of diagnosis, a single parent headed 16% of families. This was 20% by the time the survey instrument was completed. In 15% of families, the affected child was the only child; in 48%, there were two children, and in 37%, there were more than two children. The median age of the affected child at time of diagnosis was 4.2 years, ranging from infancy to 20 years. The most common tumors reported by these families were primitive neuroectodermal tumors (medulloblastoma), followed by gliomas (low grade, mixed, malignant, germ cell). A few families reported pituitary adenomas, choroid plexus tumors, and meningiomas. No parent reported spinal cord tumors. This terminology was by parent report.

Tables 1 and 2 present the two most commonly reported important problems and helpful resources for families at each phase of illness. Table 3 presents family results of bivariate and multivariate associations with stress at each phase of illness. Results of analyses for the 139 individual respondents were similar to those for the 87 families.

**Diagnosis**

A total of 87 families, representing 139 individuals and 48 mother-father pairs, responded to this phase. The two most commonly reported important problems concerned what might have caused the tumor and the manner in which the doctor communicated the prognosis. The two most commonly reported important helpful topics concerned support from family and friends and the doctor’s help in choosing a neurosurgeon.

With regard to bivariate analyses, being married (83%) versus divorced, widowed, separated, or single (17%) was significantly associated with increased stress (\( p = .03 \)). Families perceiving that the manner in which the doctor communicated the prognosis was inappropriate had increased stress (\( p = .05 \)). Results of the multiple logistic regression analysis indicated that being married was the only factor that was significantly and independently associated with increased stress (\( p < .05 \)).

**Hospitalization/Surgery**

A total of 84 families, representing 130 individuals and 46 mother-father pairs, responded to this phase. The two most commonly reported important problems were lack of training in financial and insurance matters after discharge and not having a coordinator/advocate for their child’s services. The two most commonly reported important helpful topics were availability of the nurse(s) and support from family and friends. Bivariate and logistic regression results indicated that parents who were married had significantly more stress than others (\( p = .04 \)).

**Hospital Discharge**

A total of 84 families, representing 130 individuals and 46 mother-father pairs, responded to this phase. The two most commonly reported important problems concerned dealing with the child’s personality or moods and lack of information regarding long-term effects/disabilities. The two most commonly reported important helpful topics were availability of the nurse(s) and support from family and friends and treatment of their child’s pain.

From bivariate analyses, families that cited problems dealing with their child’s personality or moods or had concerns regarding their employment had significantly more stress (\( p = .003 \) and \( p = .03 \), respectively). Families with affected children who were younger at the time of diagnosis experienced more stress than those families with affected children who were older (\( p = .03 \)).
Logistic regression results indicated that problems dealing with the child’s personality/moods was the only variable that was significantly and independently associated with increased stress (\(p < .05\)).

### Adjuvant Treatment

A total of 83 families, representing 120 individuals and 38 mother-father pairs, responded to this phase. The two most commonly reported important problems concerned dealing with their child’s personality or moods and their side effects of treatment. The two most commonly reported important helpful topics concerned support from family and friends and availability of the nurse(s).

Results of bivariate analyses indicated that lack of information regarding stopping treatment was associated with increased stress (\(p = .003\)). Families perceiving that the manner in which the doctor communicated the prognosis was inappropriate had

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**Table 1. The Two Most Commonly Reported Important Problems Among Families\(^a\) by Phase**

<table>
<thead>
<tr>
<th>Phase of Illness</th>
<th>n</th>
<th>%</th>
<th>Item</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosis</td>
<td>87</td>
<td>60</td>
<td>Information I received about what might have caused the tumor</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>The manner in which the doctor told me the prognosis</td>
</tr>
<tr>
<td>Hospitalization/surgery</td>
<td>84</td>
<td>55</td>
<td>My training to deal with financial and insurance issues after discharge</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Availability of a coordinator/advocate for my child’s services</td>
</tr>
<tr>
<td>Hospital discharge</td>
<td>84</td>
<td>49</td>
<td>Availability of help in dealing with my child’s personality or moods</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Information I received regarding long-term effects/disabilities</td>
</tr>
<tr>
<td>Adjuvant treatment(^b)</td>
<td>83</td>
<td>47</td>
<td>Availability of help in dealing with my child’s personality or moods</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Availability of help in dealing with the side effects of chemo/radiation</td>
</tr>
<tr>
<td>Recurrence</td>
<td>63</td>
<td>55</td>
<td>Information I received at the hospital on alternative treatments</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Availability of help in dealing with my child’s personality or moods</td>
</tr>
<tr>
<td>End of life</td>
<td>15</td>
<td>67</td>
<td>Information I received at the hospital regarding the dying process</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Information I received regarding alternative treatments</td>
</tr>
<tr>
<td>Remission</td>
<td>67</td>
<td>50</td>
<td>Information on possible long-term/delayed side effects of treatment(^c)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Information I received on lifetime expectations</td>
</tr>
</tbody>
</table>

\(^a\) If either the mother or the father identified the item as an important problem.  
\(^b\) Mothers experienced more stress than did fathers at this phase (\(p = .009\)).  
\(^c\) Mothers perceived this as more important than did fathers (\(p = .022\)).

**Table 2. The Two Most Commonly Reported Important Helpful Resources Among Families\(^a\) by Phase**

<table>
<thead>
<tr>
<th>Phase of Illness</th>
<th>n</th>
<th>%</th>
<th>Item</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosis</td>
<td>87</td>
<td>95</td>
<td>Support from family and friends</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>The doctor’s help in choosing a neurosurgeon</td>
</tr>
<tr>
<td>Hospitalization/surgery</td>
<td>84</td>
<td>92</td>
<td>Availability of the nurses</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Support from family and friends</td>
</tr>
<tr>
<td>Hospital discharge</td>
<td>84</td>
<td>92</td>
<td>Support from family and friends</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>The treatment of my child’s pain</td>
</tr>
<tr>
<td>Adjuvant treatment</td>
<td>83</td>
<td>89</td>
<td>Support from family and friends</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Availability of the nurse(s)</td>
</tr>
<tr>
<td>Recurrence</td>
<td>63</td>
<td>100</td>
<td>Support from clergy or through prayer</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Information I received at the hospital on alternative treatments</td>
</tr>
<tr>
<td>End of life</td>
<td>15</td>
<td>100</td>
<td>The environment in which my child was to die</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Support from clergy or through prayer</td>
</tr>
<tr>
<td>Remission</td>
<td>67</td>
<td>90</td>
<td>Support from family and friends</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Information on doctors with expertise to care for my child’s needs</td>
</tr>
</tbody>
</table>

\(^a\) If either the mother or the father identified the item as an important helpful resource.
increased stress ($p = .01$). Families with difficulties dealing with their child’s personality or moods and those with affected children who were younger at time of diagnosis experienced increased stress ($p = .04$ and $p = .01$, respectively). Lack of availability of doctors and nurses was associated with increased stress ($p = .03$ and $p = .04$, respectively). Logistic regression results indicated that lack of information concerning stopping treatment was the only variable that was significantly and independently associated with increased stress ($p < .05$).

**Recurrence**

A total of 63 families, representing 87 individuals and 26 mother-father pairs, responded to this phase. The two most commonly reported important problems concerned lack of information from the hospital on alternative treatments and dealing with their child’s personality or moods. The two most commonly reported important helpful topics concerned support from clergy or through prayer and information from the hospital on alternative treatments.

Results from bivariate analyses indicated that lack of resources related to education, child care, and family/home responsibilities as well as employment concerns were significantly associated with increased stress ($p < .05$). Logistic regression results indicated that employment concerns was the only variable that was significantly and independently associated with increased stress ($p < .05$).

**End of Life**

A total of 15 families, representing 29 individuals and 10 mother-father pairs, responded to this phase. The two most commonly reported important problems concerned lack of information from the hospital regarding the dying process and regarding alternative treatment. The two most commonly reported important helpful topics concerned the environment in which the child was
to die and support from clergy or through prayer. For families experiencing the end of life phase, no topic was found to be significantly associated with stress.

Remission

A total of 67 families, representing 99 individuals and 33 mother-father pairs, responded to this phase. The two most commonly reported important problems concerned lack of information on possible long-term/delayed side effects of treatment and on life-time expectations. The two most commonly reported important helpful topics concerned support from family and friends and availability of information on doctors with expertise to care for their child’s needs.

Results of bivariate analyses indicated that families reporting a lack of information on lifetime expectations and on doctors with expertise in child’s needs had significantly more stress ($p = .04$ and $p = .05$, respectively). Families experiencing difficulty with information obtained using the computer had significantly more stress ($p = .03$). Logistic regression results indicated that lack of information on lifetime expectations was the only variable that was significantly and independently associated with increased stress ($p < .05$).

Differences Between Mother and Father Partners

To better understand the heterogeneity of responses within a family, differences between mother and father partners ($n = 48$ at diagnosis) were investigated. Considering the large number of outcome variables and topics, very few differences between mother-father partners were identified. At time of adjuvant treatment, there was a significant difference between the 38 mother-father partners with regard to level of stress, with mothers experiencing more stress than fathers ($p = .009$). During the remission phase, there was a significant difference between the 33 father and mother partners with regard to the importance concerning information about long-term/delayed side effects of treatment, with mothers more often perceiving this as important ($p = .022$). Also during this phase, the difference between partners with regard to the importance of availability of help with family/home responsibilities was significant, with mothers more often perceiving this as important ($p = .047$).

Discussion

Among parents with a child with a brain or spinal cord tumor, we sought to determine important unmet needs during each of the six phases of illness and their association with increased stress. Consistent patterns emerge throughout the phases of illness. First, access to information specific to each phase of illness was reported as an important problem throughout. Parents commonly reported a lack of information regarding etiology, the disease process, treatment options, and prognosis. Second, availability of support from family, friends, and clergy was perceived as helpful and important throughout the phases of illness. Third, stress appears to be exacerbated by interpersonal interactions that occur during the earlier phases of illness, regardless of whether these interactions involve the physician, marital partner, or the affected child.

Lack of important information throughout the phases of illness has been reported for other forms of cancer (Pyke-Grimm, Degner, Small, & Mueller, 1999; Tetzelaff, 1997). For parents in our study, informational needs encompassed etiology, prognosis, and treatment alternatives. Certainly, overwhelming concerns at time of diagnosis or subsequent phases of illness can predispose parents to “block out information” or forget information that has been conveyed previously. However, the majority of parents at most phases of illness felt they lacked important information. Regarding information needs for etiology and prognosis, parents need to be aware of the latest research findings, which may support or refute associations with genetic or environmental factors (Pollack, 1999; Siffert et al., 1999). With regard to course of disease, our findings indicate that parents may not have been informed about inherent changes produced by the illness and/or treatment. These results are consistent with those reported previously for survivors (Eiser, 1998). Although interest in the use of complementary/alternative treatments continues to grow, our results indicate that about half of these families have not been given choices by their health care providers that included these therapies. Furthermore, at end of life, two thirds of families reported they lacked information about treatment alternatives. Stewart and Cohen (1998) stated, “Ideally, all patients should receive the best care that science and technology can offer, and the comfort and improved sense of well-being that complementary practices can provide” (p. 39).
Half the families reported important concerns regarding changes in the child’s personality or moods. Kennedy and Leyland (1999) found that 50% of children with brain tumors studied had a high risk of clinically significant emotional/behavioral problems. Siffert et al. (1999) stated that behavioral changes often relate to raised intracranial pressure, causing intermittent pain and discomfort. The overall disease process as well as medical and surgical interventions will likely affect the child’s neurocognitive functioning, resulting in changes in the child’s personality and moods (Levine & Zuckerman, 1999; Mulhern et al., 1999; Pollack, 1999). Children with brain tumors may differ in this way from those with other forms of cancer, and it appears from our results that parents had not been prepared for these changes.

Although marriage can extend the social support system of parents, our findings show that parents who were married had significantly more stress than those who were single, divorced, or widowed. One possible explanation, as discussed by Binger et al. (1969) in their report of parents of children with leukemia, is the difference in coping strategies between mothers and fathers. They stated, “The fathers found many ways to absent themselves from painful involvement with their troubled families. Such avoidance, however, often leaves the mother bereft of much needed support” (p. 416). Another possible explanation is that differences between mothers and fathers with regard to treatment and lifestyle expectations may exacerbate marital stress. Our results indicate that mothers more so than fathers placed significantly more importance on possible long-term outcomes of treatment and on availability of help with family/home responsibilities. Stress levels of mothers were significantly greater than those of fathers during adjuvant treatment. Distress between married partners of chronically ill children has been described (Sabbath & Leventhal, 1984). However, to our knowledge, the current study is the first to compare these traditional families with those with alternative structures in this context.

Finally, support from family and friends was the most important helpful resource. However, neither social support nor availability of counseling services was found to be significantly associated with decreased stress. This is consistent with the findings of Sawyer, Antoniou, Toogood, Rice, and Baghurst (2000) in that support did not alleviate the perceived problems faced by the majority of families.

Limitations

The study design has several limitations. First, generalizability may be limited because the sampling frame used was the northeast region of the United States. However, this design is consistent with the recognition of regionalization of cancer care (American Academy of Pediatrics, 1997; Wolfe et al., 2000). Second, because the sample is composed of those who chose to complete the survey—even though various recruitment strategies were used—it is acknowledged that the resulting sample may not be representative. Third, another source of bias exists in that respondents were asked to recall events (often emotional) that occurred as long ago as 10 years prior. It is possible that responses may reflect more about the duration of stressors since the event rather than those present at the time of the event. This may involve the concept of response shift (Breetvelt & Van Dam, 1991) that was not controlled for in the study design. Fourth, items listed on the survey instrument may be interpreted differently among respondents, and further qualitative research may provide more complete interpretations of the concerns. Fifth, because families were requested to complete only those survey pages that corresponded to phases they experienced, certain phases had smaller sample sizes. However, with the exception of the end-of-life phase, statistically significant associations between survey items and stress were present for all other phases of illness.

Implications for Care

We acknowledge that health care staff members do provide parents with information at various times during a child’s illness. However, discussions concerning the relative efficacy of treatment options, safety concerns regarding risks and side effects of treatment, as well as inherent short- and long-term effects of the disease need to be initiated more frequently and tailored according to the content of material and learning style of the parent. These discussions must reflect the coordination of care across the phases of illness (Hellsten, 2000), as well as the abilities of these parents to comprehend the concepts, facts, and uncertainties. We propose that health care professionals should be made more aware of the needs commonly reported by families so that they can develop individualized plans to educate parents as adult learners. This plan can be modeled
after Knowles’s andragogical model of adult learning (Linscott, Spee, Flint, & Fisher, 1999), which postulates (a) self-concept moves from dependence to self-directing, (b) adults have a knowledge base (reservoir) of resources, (c) readiness to learn is related to social roles, and (d) immediacy of application is preferable for learning. Assessment of the parents, which includes educational and occupational history, social and family history, and emotional developmental level, is the primary step. Discerning the scope and/or content, the time when “readiness” to comprehend is maximized, to whom information is provided, as well as the environment in which discussions are initiated all have an impact on the understanding and retention of information.

Our findings indicate that the content of informational needs varied across phases of illness. Given the scientific uncertainty surrounding disease etiology (Siffert et al., 1999), such uncertainty transmitted to parents may contribute to their increased stress. Again, health care providers can better communicate with parents by providing them with current written materials that describe specific research studies and findings concerning environmental, genetic, and other suggested risk factors (Packer, 1999). Discussion of alternative therapies should be considered in conjunction with traditional treatments, if only for palliative purposes. Including a hospice representative as a member of the team during end-of-life care, either in the hospital or at home, may promote communication, provide information more effectively, and assist families in formulating decisions (Byock, 1999). Staff trained in medical informatics can help parents screen public medical information databases. Staff involvement is essential for critical review and correct interpretation of information from the Internet.

Changes in the child’s personality or moods can best be managed if the parents can anticipate their occurrence. This identified problem requires interventions that incorporate both educational and psychosocial resources.

Our study reported that employment concerns were significantly associated with more stress. Langton (2000) cited that decisions about continuing or reducing work commitments and coordinating work responsibilities with hospital visitations and other family needs can cause parents a great deal of anxiety; she reported that these decisions are often based solely on financial concerns. Discussions need to be initiated concerning financial and emotional trade-offs and job sharing, in addition to helping the family navigate through systems of public and private entitlements.

Faulkner et al. (1995) emphasized the plight that single parents have in bearing the burden alone and/or negotiating with or providing information to the former partner. Our findings, however, indicate that married parents experienced greater stress during particular phases of illness than did single parents. Early identification by hospital and community-based social workers, clergy, and patient advocates of marital stress is needed. Support groups and other services may help partners discover better ways of deriving support from each other (McGee & Burkett, 1998). Staff should also be alert to signs that parents may need psychiatric intervention (Binger et al., 1969; Sawyer et al., 2000). Accurate assessment of psychosocial stressors and reactions of children with cancer and their family members is a primary concern of the pediatric oncology nurse (Hendricks-Ferguson, 2000). Finally, it is important that hospital staff continually recognize the importance of the family’s social support network by liberalizing visiting hours, creating comfortable and stimulating environments for children, encouraging social networks with other families, and providing psychosocial support services.

Conclusions

This study provides evidence of specific and general concerns identified by parents of children with brain tumors. These results allow medical providers to design, implement, and evaluate interventions to help meet the needs of these families during all phases of illness.

Acknowledgments

This work was supported by a grant from the Children’s Brain Tumor Foundation. We thank Dr. Shlomo Shinnar and Dr. Ruth Stein for their invaluable comments in the design and editorial phases of the study. We also thank the families that participated in this study, without whom this study would not have been possible.
References


Hellsten, M. B. (2000). All the king’s horses and all the king’s men: Pain management from hospital to home. *Journal of Pediatric Oncology Nursing*, 17, 149-159.


Most children diagnosed with cancer will become survivors of their disease. However, a large number of these children may be at risk for the development of late complications. It is not clear whether these survivors and their families are aware of their treatment history including diagnosis, treatment, and the late complications of their treatment. The purpose of this needs assessment was to ascertain survivors’ knowledge of their disease, the various treatment modalities, and whether they were aware of their individual risks for developing late complications of their treatment. A brief six-item questionnaire was developed to determine survivors’ knowledge of their cancer treatment and to be completed just before at their survivor visit. A total of 141 survivors completed this questionnaire. The mean age at diagnosis was 6.8 years, and the median age at the time of this assessment was 16 years. Although all of the subjects stated they knew their disease, only 84% (n = 118) listed their diagnosis. The majority of the survivors knew they received chemotherapy, but only 50% were able to list one or more specific drugs they received. Further lack of knowledge was also evident for survivors who received radiotherapy. The results of this assessment represent a lack of knowledge especially of the survivors’ individual risk for developing late complications of their therapy. Education about late complications of therapy should be introduced early and often such as at diagnosis, within months of the completion of therapy, and during every survivor clinic visit. A complete treatment summary should be provided to all survivors. This summary should include the survivors’ individual risks for developing late complications and how their own health behaviors may influence the development of these late complications.

Key words: childhood cancer, survivors, knowledge

Background and Significance

Many of the more than 200,000 long-term survivors of childhood and adolescent cancer are experiencing a high quality of life. It is still unclear as to whether the majority of these individuals generally observe healthy lifestyle behaviors including eating a low-fat, high-fiber diet; exercising regularly; and not using tobacco. More important is the issue of childhood and adolescent cancer survivors’ awareness of the potential late effects of their cancer treatment that may enable them to better understand the importance of engaging in healthy behaviors that may affect their long-term survival.

Many children diagnosed and treated for cancer prior to the 1980s were not as likely to become long-term survivors as are children treated in the 21st century. It is only in the past 10 years that we have seen great advances in the treatment of childhood cancer with...
the addition of more potent chemotherapy drugs and better treatment combinations. Children are not only experiencing a greater opportunity for survival but a greater risk of toxicities of their cancer treatment. Adolescents especially received very high doses of chemotherapy, including anthracyclines, in the treatment of childhood cancers. In addition to the effects that doxorubicin has on cardiac function, the impact of smoking, unhealthy diet, and obesity could be fatal. It is important to ascertain what information survivors know about their disease and their risk for late effects and then to discuss their individual risks for the development of late complications.

This author could find no literature examining the knowledge that childhood and adolescent cancer survivors have about their disease, treatment, and the associated late effects. Most recently, the Childhood Cancer Survivor Study Group evaluated the knowledge of childhood cancer survivors about their diagnosis and treatment. Results of this study showed significant knowledge deficits among adult survivors of childhood cancer regarding their disease and treatment (Kadan-Lottick et al., 2002).

These young adult cancer survivors are a captive audience during their annual follow-up visit. Nurse practitioners or other health care members should use this time during the clinic visit to educate these young adults about the importance of healthy lifestyle behaviors to either reduce their risk of developing late effects or prevent them altogether. The information provided should be accurate and concise to avoid bombarding these busy young adults with too much to process.

**Purpose**

The purpose of this needs assessment is to describe what the childhood and adolescent cancer survivors evaluated in the Life After Cancer Program (LACP) know about their type of cancer, treatment, and potential late effects of treatment. The LACP uses this information to both redirect any misconceptions these survivors have about their cancer history and provide a complete treatment summary including chemotherapy and other treatment modalities and risks for late effects. The primary focus of this survivor program is health promotion, but without significant knowledge of their past history and the effect on their current health, childhood cancer survivors may not begin to consider the impact of their behaviors on their health. The treatment summary provided for each survivor in this program also includes a short list of healthy lifestyle behaviors in which the cancer survivor may want to consider participating.

**Methods**

The subjects were asked six questions regarding their cancer diagnosis, treatment, and late effects. The sixth question asks whether their physician discussed any potential late effects of treatment (see Table 1). This last question was asked to assist our hematology and oncology program in better discussing and describing the various late complications of the cancer therapy we propose to our children with cancer. Survivors 16 years and older were asked to attempt to complete this questionnaire on their own. We wanted older adolescent survivors to complete their own questionnaire to obtain the best representative sample from both parents and adolescents. It is important to ascertain that adolescents and young adults know about their past cancer history and risks for late effects of their therapy. The questionnaire was validated by three cancer survivors and their parents as to the content of the questions.

From January 1, 2001, until December 2002, more than 190 survivors were seen in the LACP. One hundred forty-one survivors seen in the LACP completed this questionnaire. Subjects who placed their name on the form, were non–English speaking, or had no response to one or more of the questions were excluded from further analysis. Reasons for not completing this form included “not interested.” Each parent or survivor was given the questionnaire and an explanation of the purpose of this needs assessment when he or she arrived at the clinic. By completing the questionnaire, each subject or parent gave permission to use his or her responses in our needs assessment as explained in the attached letter to the questionnaire.

**Results**

The results of this needs assessment clearly represent a lack of knowledge of the potential late complications of cancer therapy of the childhood cancer survivors and their parents. First, the data found in Table 2 represent the differential diagnoses, age at the
The time of diagnosis, and the time of the clinic visit for the 118 survivors who actually stated their cancer diagnosis. The majority of survivors had all \( n = 53 \), non-Hodgkin’s lymphoma \( n = 12 \), Wilms’ tumor \( n = 11 \), and Hodgkin’s disease \( n = 11 \). The median age at the time of this study was 16 years, with equal representation of both the young childhood cancer survivors and older adolescents and young adults in two separate groups. Those survivors with osteogenic sarcoma, Ewing’s sarcoma, acute myelogenous leukemia, and non-Hodgkin’s lymphoma were the most knowledgeable about their risk for late effects. This may represent the fact that, namely, survivors of osteosarcoma and Ewing’s represented in this sample have experienced either the most visible or most ominous late complications from their disease and treatment. The years from completing treatment for these survivors ranged from 4.6 to 14.4 years. The median years from completing treatment for the whole group of LACP survivors seen was 8.1 years.

The information presented in Table 3 represents the general knowledge of 141 survivors of their diagnosis, treatment, and potential for late effects. Even though all \( n = 141 \) of the survivors or parents checked that they knew their cancer diagnosis. However, 22 (16%) of these survivors did not write down their diagnosis. Some of the survivors could not remember their disease or stated their “mother has it at home.” Almost all of

### Table 1. Questionnaire: What Do You Know About Your/Your Child’s Illness, Treatment, and Potential Medical Problems?

<table>
<thead>
<tr>
<th>Question</th>
<th>Y</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you know what type of cancer you had? If yes, what was it?</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>Do you know what treatment you received? (chemotherapy, surgery)</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>Did you receive radiation treatment?</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>Do you know what your dose of radiation treatment was and what it radiated?</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>Are you aware of any late effects of treatment?</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>Had your doctor discussed with you your potential for late effects?</td>
<td>Y</td>
<td>N</td>
</tr>
</tbody>
</table>

### Table 2. Demographic Characteristics of Survivors Seen to Date in the Life After Cancer Program (LACP) Who Have Completed the Questionnaire (With Definitive Knowledge of Their Disease)

<table>
<thead>
<tr>
<th>Disease</th>
<th>Number of Patients</th>
<th>Mean Age at Diagnosis (years)</th>
<th>Age at Time of Study</th>
<th>Average Years Off Treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acute lymphoblastic leukemia</td>
<td>53</td>
<td>4.8</td>
<td>35 19 7.2</td>
<td></td>
</tr>
<tr>
<td>Acute myelogenous leukemia</td>
<td>8</td>
<td>6.4</td>
<td>3 6 11</td>
<td></td>
</tr>
<tr>
<td>Wilms’ tumor</td>
<td>11</td>
<td>3.3</td>
<td>7 4 9.1</td>
<td></td>
</tr>
<tr>
<td>Hodgkin’s disease</td>
<td>11</td>
<td>9</td>
<td>– 11 6.4</td>
<td></td>
</tr>
<tr>
<td>Non-Hodgkin’s disease</td>
<td>12</td>
<td>11</td>
<td>6 11 7.4</td>
<td></td>
</tr>
<tr>
<td>Osteosarcoma</td>
<td>4</td>
<td>11.5</td>
<td>1 3 8.2</td>
<td></td>
</tr>
<tr>
<td>Ewing’s/primitive neuroectodermal tumor</td>
<td>3</td>
<td>7.8</td>
<td>1 2 14.4</td>
<td></td>
</tr>
<tr>
<td>Hepatoblastoma</td>
<td>2</td>
<td>3.7</td>
<td>2 – 4.6</td>
<td></td>
</tr>
<tr>
<td>Rhabdomyosarcoma</td>
<td>5</td>
<td>7.2</td>
<td>4 1 7</td>
<td></td>
</tr>
<tr>
<td>Chronic myelogenous leukemia</td>
<td>1</td>
<td>12</td>
<td>– 1 5</td>
<td></td>
</tr>
<tr>
<td>Neuroblastoma</td>
<td>5</td>
<td>4c</td>
<td>2 – 6</td>
<td></td>
</tr>
<tr>
<td>Medulloblastoma</td>
<td>1</td>
<td>11</td>
<td>– 1 13</td>
<td></td>
</tr>
<tr>
<td>Germ cell tumors</td>
<td>2</td>
<td>10c</td>
<td>2 – 10</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>118</td>
<td>6.8</td>
<td>52% 48% 8.1</td>
<td></td>
</tr>
</tbody>
</table>

a. Mean age at diagnosis for the whole group of LACP patients seen during the study period.
b. Mean years off treatment for the whole group of LACP patients seen during the study period.
c. Months.
d. Percentage of survivors younger than 16 years of age and those older than 16 years of age.
the subjects recalled that they had received chemotherapy as part of their treatment. However, only 50% of the survivors could list one or more specific chemotherapy agents. Only 30% ($n = 42$) of survivors or their parent knew their risk for developing late effects. Of those survivors who knew their risk for developing late complications of cancer therapy, 48% (20 of 42) were able to list more than one late effect they may be at risk for developing.

This information is surprising given the fact that many of the young adult cancer survivors seen in LACP had been off treatment for more than 7 years and at least 20% of them had been lost to follow-up for more than 2 years. One may expect that these survivors would have little to no knowledge of their cancer treatment history. However, it is of concern that only 30% (42) of childhood cancer survivors and/or their parents knew their individual risk for late effects of their cancer therapy. Almost 70% ($n = 100$) of survivors seen in the LACP stated this information was provided to them during cancer treatment. This is unexpected given the number of survivors who had no knowledge of their risk for late effects of their therapy. It is not known specifically whether this information was given only at the time of consent for treatment or discussed at sometime or other during the treatment and since forgotten. Certainly, it is apparent that these survivors require ongoing review of their individual risks for late effects of their cancer treatment, both during and following the completion of their therapy.

**Discussion**

This group represents many of the young adult population we are now seeing in our survivorship clinics. Their ability to recall their cancer history without prompting was interesting; however, the finding that only 30% of this small cohort of patients were able to remember or even be aware of their risk for developing late effects was concerning. It is clear that we, as professionals providing cancer treatment, need to expand our survivorship teaching long before therapy concludes. Choosing the best time to introduce cancer survivorship issues should be well thought out with consideration to the individual’s treatment course. Providing the parents and survivors with a comprehensive cancer treatment summary is vital, and continued review of their treatment history is important as this population ages.

It is important to note several limitations of this study. First, it is unclear how much influence parents had on the adolescent’s completion of this form, as no medical personnel supervised its completion. Second, most parents of children and adolescents who are diagnosed with cancer as well as the adolescents are devastated with the diagnosis of cancer and do not retain more than 10% to 15% of what is told to them during the initial diagnosis and consent. It is hoped that their physicians may have discussed the importance of long-term follow-up and risk for late effects throughout their treatment as well as at the off-therapy evaluation. Last, this study represents a very small number of childhood and adolescent cancer survivors, and therefore we cannot make definitive assumptions about the knowledge of late effects of all cancer survivors.

We have begun to use this information to present childhood cancer survivorship information to our newly diagnosed cancer patients early in their cancer treatment. Information about our program as well as general information about survivorship will be given to parents at the time of diagnosis. More detailed information about late effects and the importance of long-term follow-up that is found in the LACP brochure will be provided at the end of treatment evaluations. Furthermore, our program is in the process of reimplementing the Transitional Off-Therapy Program for Survivors of Pediatric Cancer. It is our hope that this early introduction to cancer survivorship issues will enable parents of young children and adolescents with cancer to assimilate...
survivorship information throughout the treatment as well as during the transition from therapy to survivorship. Furthermore, information is power. We hope that all childhood and adolescent cancer survivors who are aware of their potential risk for late complications will begin to engage in healthy lifestyle behaviors that may potentially reduce the risk for these complications and optimize organ function. I would encourage all nurse practitioners and nurses who are involved in the management of the needs of long-term survivors of childhood cancer to begin early discussion of survivorship issues for children currently undergoing active cancer treatment.

Reference

**Adventure Therapy: A Mental Health Promotion Strategy in Pediatric Oncology**

Iris Epstein, MN, RN

*In adventure therapy (AT), health professionals and adolescents with cancer come together to explore the wilderness of nature. One goal of this therapy is to encourage the adolescents to enhance their self-concept as part of an overall physical, cognitive, emotional or spiritual, social and psychological, or developmental rehabilitation that promotes health. The adolescents with cancer who participate in AT also learn about themselves through self-evaluation, self-exploration, self-reevaluation, self-acceptance, and self-realization. Mental health promotion (MHP) is considered a perspective and a strategy to promote health. An AT experience could be an example of an MHP initiative in which nurses can take a leadership role in participating, and further investigating, the health effects of AT on adolescents with cancer.*

**Key words:** self-concept, summer camp, adventure therapy, health promotion, adolescents

With advances in technology, the survival rate of childhood cancer is increasing, but treatment and follow-up are lengthy, often making cancer a chronic rather than fatal illness (Yeh, 2001). When cancer becomes a chronic illness, coping becomes a major priority for the adolescent, his or her family, and health care professionals.

Understanding the development of self-concept in adolescents with cancer becomes an important component in helping them learn to cope. Self-concept, defined as how adolescents feel about themselves (Piers, 1984), is affected by many psychological and social factors that in turn are influenced by the individuals’ attitudes and beliefs. A positive self-concept is generally associated with increased coping abilities (Mosher & Moore, 1998). However, recent studies have demonstrated that adolescents experiencing cancer often have low self-concept (Kameny & Bearison, 2002).

Mental health promotion (MHP) is a recent emerging perspective that has been used in the academic arena, health care setting, policy circles, and community programs (Hodgson, Abbasi, & Clarkson, 1996). MHP applies to the whole population in the context of everyday life and often refers to various strategies that can strengthen individuals’ ability to bounce back from adversity (Galbally, 1994; Willinsky & Pape, 1997). MHP aims at augmenting the actual and felt power of individuals by supporting their own intrinsic resourcefulness (Jobert & Raeburn, 1998). Adventure therapy (AT) is an emerging intervention strategy of MHP designed to empower adolescents and in the process increase their self-concept.

To ensure that MHP efforts are relevant to adolescents, it is important to identify the multiple issues related to their cancer experiences (Willinsky & Pape, 1997). One in every 1,000 young adults between the ages of 20 and 29 years is a survivor of adolescent cancer (American Cancer Society, 1999). The most recent survival rates are now approaching 70% (Eiser, Hill, & Blacklay, 2000). However, there has been an increase in the incidence of cancer in adolescents over the past 25 years, whereas the increase in survival rates has been significantly lower than in younger and older cancer patients (Eiser, Hill, & Vance, 2000). The possibility of disease-free survival is common, and these adolescents now face a different group of stressors and...
issues that did not exist previously when mortality rates were higher.

In Western society, adolescence is considered a unique stage in the human developmental process, which includes rapid physical, sexual, and cognitive growth (Ritchie, 2001). Adolescents who are either newly diagnosed with cancer or are survivors of cancer experience multiple physical, social, cognitive, and psychological issues that relate to their mental health during the cancer illness experience (Enskar, Carlsson, Golsater, & Hamrin, 1997; Hinds, 1990). The effects of chemotherapy and radiation on physical appearance may affect mental well-being. For example, feelings of self-worth may be decreased if the adolescents perceive themselves as less attractive. Major depression and depressive symptoms also affect children with cancer. Cavusoglu (2001) reported that children with cancer have a higher incidence of depression than do healthy children. Skarstein, Aass, Fossa, Skovlund, and Dahl (2000) suggested that depression was a stronger predictor for reduced quality of life in children with cancer than was anxiety.

Pain and suffering also have an impact on the adolescent self-knowledge experiences (Kane & Primomo, 2001). Painful experiences relate to the physical pain that the cancer and the treatment cause, whereas the suffering relates to the internalized emotional suffering. Even after the acute cancer experience, adolescent cancer survivors often still feel they will not survive. Instead of spending time with their friends, these adolescents often find themselves isolated and powerless (Enskar et al., 1997; Kameny & Bearison, 2002). Despite their cancer experiences, children and adolescents strive to have a normal life (Grootenhuis & Last, 2001). The social, cognitive, emotional, and psychological issues should be considered when designing interventions to promote long-term mental health for adolescent cancer survivors. How adolescents with cancer perceive their cancer experience and how these perceptions affect them appear to play a significant role in their social adjustment and also in how the adolescents cope with cancer as a chronic condition (Grootenhuis & Last, 2001; Lazarus & Folkman, 1984).

MHP is easier to implement where the environment is flexible and accommodating (Willinsky & Pape, 1997). Such flexibility is inherent in AT where a supportive environment enhances the adolescent’s ability to cope with cancer. An array of terms are used to describe AT: *wilderness therapy* (Russell & Philips-Miller, 2002), *outward bound* (Ewert, 1983; Walsh & Golins, 1976), *adventure education* (Neill & Dias, 2001), *adventure-based therapy* (DeHart Richardson, 1998), *adventure therapy* (Autry, 2001; Gass, 1995) or *summer camp* (Bluebond-Langner, Perkel, Goertz, Nelson, & McGeary, 1989). In all of these programs, participants engage voluntarily in a natural outdoor adventure setting (Ewert, 1983). However, each program targets a different population, includes diverse physical and social activities, and consists of various professionals and nonprofessionals as support personnel. The length and site for each classification of program also varies.

In an AT experience, health professionals, guides, and adolescents come together to embark on an adventure in the wilderness of nature. One goal of such a strategy is to encourage the adolescent to enhance his or her multidimensional self as part of an overall physical, cognitive, emotional or spiritual, social and psychological, or developmental rehabilitation. Russell and Philips-Miller (2002) found that physical exercise and hiking, primitive wilderness living, peer feedback, and the supportive relationship established with wilderness guides and therapists were key change agents for adolescents with problem behavior. Similarly, Keats, Courneya, Danielsen, and Whitsett (1999) reported that structured and supportive interventions aimed at increasing the physical activities of adolescents with cancer and/or adolescents who have survived cancer promoted their mental health. Despite the benefits of AT, there are no studies that evaluated the effects of AT on child and family outcomes.

The literature suggests that overall, adolescents with various diagnoses benefit from participation in nature activity programs (Autry, 2001; Keats et al., 1999; Russell & Philips-Miller, 2002). However, most studies suffer from methodological inadequacies and fail to provide specific empirical evidence that wilderness therapy is an effective intervention that promotes health and enhances how the adolescents feel about themselves (Ewert, 1983; McKenzie, 2000). Most studies did not use follow-up measures to explore and evaluate the effects of AT on the adolescents’ self-concept after months or years. In addition, there are inconsistencies in program activities (McKenzie, 2000); as a result, it becomes more challenging to generalize the effects of AT on the adolescent’s self-concept when each adventure program includes different activities.
The outcomes reported from AT or summer camps are not consistent in the literature. Nevertheless, an increasing number of AT and summer camps report that some of AT’s program characteristics bring about an increase in self-concept, but they do not specify what underlying mechanisms may account for how AT changes one’s self-concept (Ewert, 1983; McKenzie, 2000). Adolescents with cancer learn about themselves from the multiple components that AT addresses, such as the physical, social or group, cognitive, spiritual, and psychological environments. These components affect, and are affected by, each other; thus, they cannot be rigidly separated (Ewert, 1983). The hierarchy of importance changes for each individual. Some adolescents learn more about their strengths from their peers, whereas others do so from their guides or instructors. Similarly, according to a feminist framework, “self knowing is a fluid process of experiencing an ever-changing interacting sense of self that emerges in an ongoing relational context” (Welch-Ross, 2000, p. 115). Thus, in the context of AT, the adolescents with cancer are continuously evaluating their sense of self through their interaction with people and nature.

Ewert (1983) reviewed outdoor adventure studies and summarized their beneficial outcome according to four perspectives: psychological, sociological, educational, and physical. Ewert explained that there is a lack of collaboration between the disciplines in the fields of education, psychology, and sociology. Interestingly enough, there are no nursing studies done with AT. However, there are studies done with children with cancer in summer camp. Eng and Davies (1991) studied the changes of self-concept of children with cancer in a summer camp. Using an MHP framework would integrate all the disciplines, thus giving a comprehensive and innovative picture of the beneficial outcomes of AT. Nurses, physicians, educators, and psychologists can come together with mental health knowledge to develop and evaluate adventure therapy programs for adolescents with cancer.

**AT and Self-Concept**

Cancer touches every aspect of the adolescents’ lives. The current culture of the health care system is focused on curing the cancer but has failed to address issues related to the person behind the cancer. Caring for the adolescents with cancer in an environment away from the hospital will provide a better opportunity for reflection and reevaluation of the adolescents’ abilities. In AT, the adolescent is surrounded by the beauty of nature, interacting with other adolescents with cancer, and is supported by the multidisciplinary team. This environment can help the adolescents reevaluate their lives by focusing on the things they can do. There are many variables (self, peers, nurses, nature) that can contribute to the adolescents’ self-concepts.

**The Self**

Each person is unique and at different times will respond differently to the same events (Lazarus & Folkman, 1984). Sense of self depends on the child’s knowing how to act within their social and physical world, which depends on the child’s developmental age (Welch-Ross, 2000). Not only does developmental stage affect self-concept outcome, but other factors such as age, gender, cultural background, and the expectations of participants may influence the degree to which the adolescent’s self-concept changes after or during AT (Ewert, 1983).

The effect of the participant’s gender on AT outcomes has been addressed (Witman, 1995). It was suggested that females valued “trust activities,” whereas males valued activities that relate to power or dominance. Thus, males and females tend to react differently to the AT experience. Males may seek more challenges and adventures in AT experiences whereas females look for more spiritual development. Further studies need to explore the effects of gender on participants’ behaviors in AT.

**Social Sense of Self**

Adolescents with cancer can learn about their experiences and strengthen their control over their situation by engaging with other adolescents who have experienced cancer (Kameny & Bearison, 2002). AT facilitates the establishment of friendships among adolescents who have experienced the same or different cancer experiences. These adolescents learn about themselves through social interactions. These social interactions also serve to increase the cognitive and educational abilities of the adolescent. Bluebond-Langner et al. (1989) reported that the focus of summer camp is different in that summer camp increases the child’s knowledge of cancer and its treatments.
Welch-Ross (2000) explained that self-understanding grows through empathetic understanding of others’ subjective experiences in a variety of contexts with particular people. Welch-Ross noted that “the self becomes remembered according to the agreements reached with others about the meaning of past experience” (p. 117). Sharing past experience in an AT setting might have an effect on how the adolescent remembered himself; he might remember himself as a strong person or as not so strong. As well, sharing experiences with others who have cancer contributes to the personal relationships that develop between individual group members (Conrad & Hedin, 1981). However, in AT, adolescents with cancer can share stories of their experience in living with cancer. If these stories could be disseminated more widely, AT could be the forefront of promoting peer acceptance and discouraging prejudice (Russell & Philips-Miller, 2002).

Nurses’ Effect on Sense of Self

Nurses can play a leadership role in the AT setting, not only caring for the physical need of the adolescents in a summer camp or AT context but also caring for spiritual, social, and emotional needs. In an AT context, the instructor or guide traditionally takes the leadership role. The interpersonal interactions of instructors are also thought to influence program effectiveness and self-concept (Bartley & Williams, 1988). By having high yet attainable expectations of participants, the instructor creates a type of self-fulfilling prophecy (Riggins, 1986). When the instructor is accepting, genuine, and empathetic, there is an incentive for participants to grow and become empowered (Russell & Philips-Miller, 2002). Empowering the individual is a key concept in MHP. In a supportive environment, adolescents with cancer can learn about things that they can achieve despite their illness.

Bacon (1983) explained that the self, peers, and the instructors all can facilitate learning in an AT setting through the conscious use of metaphors. For example, at the beginning, adolescents can reflect and internalize meaning from the AT experience according to the “Mountains Speak for Themselves” model, in which participants are responsible for reflecting on their own. For example, when the adolescent experiences the beauty of nature, they might assign a unique meaning to this pastoral experience. Some might think to themselves, “This mountain is too difficult to cross; I cannot do it.” Others might see the same mountain and say, “This mountain is difficult, but I will give it a try.” Another way to process the information in AT is named the “Outward Bound Plus” model. In this model, the instructor takes the role of discussion leader and provides information regarding crossing the mountain. The third model encompasses a mix of the two different techniques from the Outward Bound Plus and the Mountains Speak for Themselves models (Bacon, 1983). For example, the adolescents assimilate the techniques given by the instructor on how to cross a mountain and reevaluate their abilities.

Nature and Sense of Self

The healing effect of nature on the self is a relatively recent area of research in the field of ecopsychology (Duncan, 2002) and geography (Gesler, 1992). Getting away to a quiet, nonurban, slower-paced environment is deeply restorative (Duncan, 2002). Some attempt has been made to quantify the effect of the outdoors in a scientific way. For example, the effects of the sun and daylight on health have been studied intensively. It is a documented fact that the sun affects mood (i.e., seasonal affective disorder or winter depression), energy, and sleeping pattern levels (Lindsley, 2003). Sunnvison and Ekman (2001) demonstrated the positive influences of the environment on the elderly with Parkinson’s during a walk in the Swedish mountains. Russell and Phillips-Miller (2002) reported the positive effects of wilderness experience on adolescents’ behavioral change. In Canada, Sylvain Baruchel, director of the new agent and innovative therapy program and staff oncologist in Toronto’s Hospital for Sick Children, has pioneered an adventure therapy program for adolescents with cancer and sees first hand the healing power of nature (Stevens et al., 2004). Therefore, not only are activities beneficial, but simply being outside and surrounded by the beauty of nature provides the participant with opportunities to stop, think, and reflect and optimally become healthy. Gesler (1992) emphasized that it is not only nature that might contribute to enhancing health but also place. Individuals behave in certain ways in certain places. A natural setting provides meaning for people in various ways: through identity and feeling of freedom or expression of spirituality (Gesler, 1992).
Spirituality and Sense of Self

The aesthetic and spiritual qualities of the wilderness environment are considered by some to enhance self-restoration and transformation (Hattie, Marsh, Neill, & Richards, 1997). Through participants’ exposure to nature and interactions with people, AT instills some degree of hope. The spiritual dimension is thought to integrate all human dimensions (mind, body, and spirit) for a sense of wholeness and mental health well-being. The spiritual dimension incorporates a sense of hope and self-worth, meaning and purpose, and interconnectedness with others (Davies, Brenner, Orloff, Summer, & Worden, 2002).

Some of the adolescents with cancer who take part in AT will die young. When these adolescents are in an environment of trust that is nonjudgmental and if the issue of death comes up, they may feel more comfortable talking about it either with other adolescents, guides, or health professionals. Talking about the possibility of dying and relating feelings about friends who have died can be an adaptive way of coping with the suffering experiences of cancer (Kane & Primomo, 2001). Encountering the possibility of death brings an individual in touch with the destiny of knowing self-doubt, agony, sadness, and pain. In Western culture, the self is portrayed as strong, self-reliant, and independent, but we are also socially dependent (Carnevale, 1999). Things happen to each person; therefore, it is not our fault if one becomes ill. AT promotes a balanced sense of self in relation to others and facilitates time for reflection and reevaluation of the self (Russell & Philips-Miller, 2002). Rather than fostering a mutual pretense and a conspiracy of silence in which death or cancer is not mentioned, AT may shed some understanding on the emotional and spiritual struggle involved with the process of dying. However, longitudinal studies need to be implemented to see how AT affects adolescents over the long term and, specifically, how memories of the AT persist and are therapeutic over time.

Doing physical activities has been demonstrated to increase well-being in adolescents with cancer (Keats et al., 1999). A number of theorists have suggested that an unfamiliar physical environment causes participants to experience a state of dissonance. By overcoming dissonance through the mastery of the tasks presented by the environment, participants are believed to experience positive benefits and increased self-concept (Gass, 1993). Most AT has a physical activity component that takes place in the outdoors and may include hiking, canoeing, and rock climbing, all of which can engender the participants’ emotional, spiritual, and physical growth. For example, an adolescent who was able to participate in a hiking trip might believe that she is stronger physically and spiritually and that she is not as helpless as she thought she was. Increased physical fitness is an important factor related to the development of self and the psychosocial well-being of adolescents with cancer (Courneya, Mackey, & Jones, 2000). Physical exercise can also be an outlet for depression and anxiety (Walters & Williamson, 1999). Usually, the adolescent with cancer is prone to depression and is in poor physical shape as a result of the various medications and the disease process (Walters & Williamson, 1999).

Physical and mental challenges that occur due to physical activity are thought to have the greatest influence on self-concept if they increase incrementally. In AT, challenges are structured so that they appear to be increasingly strenuous just as the participant masters a new skill, and a more challenging activity is required to achieve the same level of dissonance (Gass, 1993). Being able to perform challenging tasks is related to a greater sense of control over one’s body, which fosters more perception of control in other areas. For example, if adolescents reflect on their successful physical accomplishments, they may conclude from these experiences, “If I have cancer and I can climb this tall mountain, maybe I underestimated my self-capabilities.” MHP directs the adolescents to appreciate the positive quality of life that extends beyond the mere absence of a problem.

Self-concept is a multidimensional concept (Mzobanzi, 1999). AT can increase the multidimensional self-concept of the adolescent (Russell & Philips-Miller, 2002). The self-concept of adolescents who have been through a summer camp and AT experience has been systematically investigated in a few studies. The results were mixed: Some studies indicated that self-concept scores did not change before or after a summer camp (Benson, 1987), whereas others reported a significant change in self-concept (Bluebond-Langner et al., 1989; Eng & Davies, 1991; Keats et al., 1999).

The basis for these inconsistent findings may lie in the various tools and sample sizes that are used to measure and define self-concept. For instance, Benson (1987) studied the relationship between self-concept and a summer camping program for children and adoles-
cents with cancer. She used the Piers-Harris Children’s Self Concept Scale (CSCS) (Piers, 1984) with a sample of 13 children and reported no changes in self-concept before and after the summer camp. Conversely, Eng and Davies (1991) used the Piers-Harris CSCS and human figure drawing (Koppitz, 1984) on a sample of 69 children aged 6 to 16 years and concluded they had a more positive self-concept following their camp experience. Thus, a specific summer camp for children with cancer provides opportunities to decrease anxiety through the sharing of common experiences in a safe and normalized environment and contributes to learning new coping strategies and enhances self-concept. Keats et al. (1999) used a measure of overall self-concept, the self-description questionnaire (Marsh, 1992), with a sample of 53 adolescents with cancer and found that those who maintained a physically active life before their cancer and during and after their cancer treatments report better general self-concept.

However, most studies ignore the multidimensionality of the construct. Based on this multidimensionality, self-concept cannot be captured in a single measure. How one feels about oneself is always changing and is influenced by interactions with people, nature, and self. Future studies should use a variety of research approaches and techniques, both qualitative and quantitative, at different points in time. For example, studies should not only explore changes in self-concept before and after summer camp but also explore changes 3, 6, and 9 months after the experience.

The research literature is also limited to outdoor adventures that focus on self-concept in relation to the specific discipline issues but not in relation to program issues such as the length of course, mix of activities, and instructional staff (Ewert, 1983). For example, Roy’s (1976) adaptation model dissected self-concept into two components: a physical and a personal self. Nursing research on summer camp (Bluebond-Langner et al., 1990; Eng & Davies, 1991) focused on the psychological self, virtually excluding the relationship to program issues such as how the length of the camp affected the children’s self-concept. In psychology, most studies use self-reported psychological measures to quantify self; little research has been conducted on the nature of, or reason for, any observed change in relation to the type of activities, (e.g., physical activities, social gathering activities) (Briery & Rabian, 1999).

From the education perspective, the process of decision making and problem solving has been explored but not in relation to how and what in AT affects the process of decision making (Galloway, 2002).

Willinsky and Pape (1997) argued that it is difficult to evaluate the exact effectiveness of MHP activities because there are many variables involved at a particular time. For example, two adolescents with similar age and type of cancer will appraise their experiences with cancer in different ways depending on their support system or other events that happen in their life (e.g., another family member is sick, financial needs). Every child is unique, and for some adolescents, being away from their familiar surroundings might decrease their sense of control and increase their anxiety. Concepts of self, such as self-confidence and self-actualization, are impossible to observe and quantify and are difficult to evaluate and study (Smith, 2001).

Conclusion

AT has evolved into a discrete field, with objectives most closely related to mental health and practices most closely related to the disciplines of nursing, education, and psychology. Nurses may be interested in AT because it includes both support for and attempts to address issues of the whole person. In the AT setting, nurses are better able to know the person beyond the cancer diagnosis. Educators are interested in AT because it provides an environment for increased problem-solving skills and knowledge regarding nature (Hattie et al., 1997). In an AT experience, the place of health care is being shifted from an environment that focuses on curing and fighting the cancer to a natural environment that focuses on being empowered by the cancer experience. Focusing on the positive events in life and being empowered by them is the essence of MHP and AT (Magyary, 2002). AT experiences for adolescents with cancer provide them with opportunities for self-evaluation, self-exploration, self-reevaluation, self-acceptance, and self-realization. What adolescents with cancer think and feel about themselves is a very strong determining factor in their overall adjustment and achievement in life (Courneya et al., 2000; Lazarus & Folkman, 1984). Therefore, all the various components of AT are considered to influence the self-concept of the adolescents. Nurses should consider taking an active part in AT and further study its effects on adolescents with cancer. As well, future research should apply not only well-established self-concept tools when evaluating
self-concept in these adolescents but also qualitative methods to further explore the effects of AT on the multidimensional aspects of the adolescent’s self-concept. Data should be obtained from participants, instructors, and research observations. Studies should explore the long-term effects of AT on self-concept, as well as the specific program characteristics that influence the multidimensionality of self-concept. In this way, specific program activities could be linked to specific dimensions of self-concept and improve an adolescent’s coping skills.

References

Epstein


