

Psychosocial Support for Patients in Pediatric Oncology:
The Influences of Parents, Schools, Peers, and Technology

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Abstract

The diagnosis and treatment of pediatric cancer can be associated with profound psychosocial changes in the life of young patients. While nurses, physicians, and other healthcare professionals are important sources of support, psychosocial support is also available through parents, schools, and peers. This article presents a review of the literature on how parents, schools, and peers affect the coping and adjustment of young patients with cancer and critically reviews interventions directed at improving functioning in these areas. Special attention is paid to recent interventions that exploit technology such as video games, CD-ROMs, and the Internet to provide creative new forms of support for patients in pediatric oncology. Existing research on both technological and interpersonal forms of intervention and support show promising results, and suggestions for further study are provided.

Keywords: children, adolescents, pediatric, cancer, intervention, parents, school, peers, technology, Internet, video games, psychosocial

The diagnosis of cancer in childhood and adolescence brings about many changes in the lives of young patients and their families. Patients are suddenly placed in the position of coping with a wide array of new situations, such as painful and frightening symptoms, uncertainty of prognosis, and changes in social relationships (Dunkel-Schetter, Feinstein, Taylor, & Falke, 1992). During this time, it is important to help young patients with cancer to find social and emotional support. To aid patient support, many interventions have been developed for medical personnel in hospital settings (e.g., Jay, Elliott, Woody, & Siegel, 1991; Katz, Kellerman, & Ellenberg, 1987; Zeltzer, Dolgin, LeBaron, & LeBarson, 1991). However, there are also opportunities to address issues faced by young patients with cancer as they interact with other members of their social support network. This review provides an overview of the issues that children with cancer often face with their parents, schools, and peers, and the interventions that have been conducted with these groups to aid patient adjustment. Special focus is placed on exploring the role of technology in enhancing existing support and providing new forms of support in these domains.

Parents

While parents themselves often suffer great distress over their children's cancer diagnoses (e.g., P. Sloper, 2000), they have to cope with this distress along with their responsibilities as their children's primary source of physical and psychosocial support. Children's adjustment can be affected by their parents' coping behaviors. Good coping of parents and family members, level of family support, quality of parents' marital relationship, parental cooperation and optimism, lack of concurrent stresses, and open communication within the family are all associated with

good coping among childhood cancer survivors (Kupst & Schulman, 1988; Sanger, Copeland, & Davidson, 1991). Similarly, parental coping is associated with poor outcomes in young patients, such as anxiety, hopelessness, and externalizing behaviors (Blotcky, Raczynski, Gurwitch, & Smith, 1985; Frank, Blount, & Brown, 1997; T. Sloper, Larcombe, & Charlton, 1994). The influence of fathers, along with mothers, is also important. For example, fathers' ability to maintain self-stability (e.g. keeping well groomed and in shape) is related to decreased hopelessness in patients with pediatric cancer (Blotcky et al., 1985). Thus, helping fathers as well as mothers cope with their own distress may have positive effects on the adjustment of the children themselves.

Parental Communication

Communication about cancer is one area where parents can have an impact on their children's adjustment to their illness. When parents are first told of their children's diagnoses, they face a decision about sharing this information with their children. In contrast to the past, physicians now advocate an honest and direct approach to communicating with children about cancer (Katz & Jay, 1984). There is also some evidence that young patients who are informed about their diagnosis show positive adjustment (Last & Van Veldhuizen, 1996; Slavin, O'Malley, Koocher, & Foster, 1982). However, this practice does not seem to be widespread. A questionnaire study of 51 patients with cancer in Australia (mean age = 18, mean age at diagnosis = 12.7) found that less than half of the patients felt fully informed about what was happening to them, and eight felt completely uninformed (Dunsmore & Quine, 1995).

While information about personal diagnosis and prognosis may affect patient adjustment, communication about more general cancer information seems to relate to positive outcomes as well. Greater knowledge of cancer among young patients is associated with lower levels of depression and a more positive self-image (Jamison, Lewis, & Burish, 1986; Kvist, Rajantie, Kvist, & Siimes, 1991). Furthermore, young patients with cancer who receive information about cancer and its treatment report lower levels of anxiety about treatments (Hockenberry-Eaton & Minick, 1994). Patients from families where communication about cancer is greater show a less defensive posture, closer relationships with parents, lower psychological distress, higher social competence, and basic satisfaction with the self (Spinetta & Maloney, 1978; Varni, Katz, Colegrove, & Dolgin, 1996). Thus, programs aimed at supporting parents' communication with their children in a positive and open atmosphere may be a good area for intervention. These programs should also consider tailoring the content of their communications based on certain patient characteristics. For example, there can be cultural and religious variability in people's preference for disclosing cancer information to their children (De Trill & Kovalcik, 1997). Furthermore, while open communication may be helpful overall, some patients prefer to know as little as possible about their disease (Last & Van Veldhuizen, 1996) and patients may differ in the types of information they find most helpful based on their information processing style (Miller, Fang, Diefenbach, & Bales, 2001).

Parental Support During Painful Medical Procedures

Positive coping and communication can also be promoted among parents to help alleviate their children's distress regarding cancer treatment, specifically during painful medical procedures

such as bone marrow aspirations and venipunctures. Researchers have found that parental behaviors such as agitation, anxiety, ignoring, criticism, apology, praise, and giving high levels of reassurance to young children at various times before and during painful procedures were all related to greater child distress (Dahlquist, Power, Cox, & Fernbach, 1994; Manne et al., 1992; Newby, Brown, Pawletko, Gold, & Whitt, 2000). On the other hand, talking to children in a child-centered, adult-like manner had strong associations with soothing the distress of children (Naber, Halstead, Broome, & Rehwaldt, 1995), and giving choices to children during procedures (e.g. “Which hand do you want me to look at first?”) reduced the probability of crying (Manne et al., 1992).

The use of distraction is another way for parents to ease their children’s distress during procedures. Parents who used distraction (using humor, engaging in nonprocedural talk, reading a story, etc.) had young children who had better coping behaviors and had reduced distress behaviors (Blount et al., 1989; Kazak et al., 1996; Manne et al., 1992; Manne et al., 1990; Mason, Johnson, & Woolley, 1999; Powers, Blount, Bachanas, Cotter, & Swan, 1993). (It should be noted, however, that parents, nurses, and child patients may use different criteria for measuring child distress (Manne et al., 1992), so careful thought should be given as to how distress is operationalized and measured in future studies).

Sometimes, even the simplest actions by parents can have an impact on child coping.

Adolescents with cancer stated that having their hand held (especially by mothers) was an effective coping strategy in easing treatment pain (Weekes, Kagan, James, & Seboni, 1993).

Patients said, “When my hand is held, I feel like I have someone to be my eyes... then I can trust

them to get the needle in the right place,” and, “I like to hold my mom’s hand and dig my nails into someone, it’s something to let my tensions out on” (p. 23-24). In sum, parental presence and support during painful procedures can be another way to alleviate patient distress, even among adolescents.

Parental Interventions

There are a few studies of interventions involving parents, and these interventions tend to focus on easing child distress during painful procedures (e.g., Kazak et al., 1996; Powers et al., 1993). In one such study (Manne et al., 1990), parents were trained to coach their children to use attentional distraction (children puff on party blowers), paced breathing (parents count child breaths on the blower), and positive reinforcement (children receive stickers for cooperating during the procedures) during venipunctures. Post-intervention results revealed reductions in child behavioral distress, parents’ anxiety, and parents’ ratings of child pain as compared to controls. Children’s ratings of their own pain, however, did not differ between intervention and control groups.

Other interventions focus more in improving parent and family functioning. An evaluation of cognitive and behavioral techniques to ameliorate psychological distress among parents of children with cancer showed that parents’ distress declined over time but that parents in the treatment and control groups did not differ on measures of distress during the evaluation period. (Hoekstra-Weebers, Heuvel, Jaspers, Kamps, & Klip, 1988). An intervention that focused on improving overall family functioning was also conducted in which families of children with

cancer were provided a multi-component intervention program involving social workers and hospital staff who served as liaisons between the family and physicians, provided information on physical and emotional changes that may take place, encouraged outreach to extended family and friends, assisted the family with tasks in the event of the patient's remission or death, etc (Kupst, Tylke et al., 1982). While the intervention was comprehensive, major differences were not found between intervention and control groups. Furthermore, the intervention consisted of aiding the family as a whole, and did not focus specifically on the effects of improved parental coping on the coping of their children (Kupst, Schulman et al., 1982; Kupst, Tylke et al., 1982). Taken together, these studies suggest that psychoeducational interventions for parents and other family members may be limited in their effectiveness.

Future Directions for Research on Parents

Overall, studies indicate that parental coping is associated with coping in their children, and the same applies to parents of children with cancer. As part of positive coping, parents may help to alleviate their child's distress by communicating with them openly about cancer and providing them with appropriate information. They can also help their children cope with pain and distress by practicing certain supportive behaviors. It is still unclear, however, how parents can help their children of different ages cope with cancer and how reciprocal interactions within the family unit as a whole (parents, siblings, grandparents, etc.) may affect the support processes of children (Kazak & Nachman, 1991; Michael & Copeland, 1987; Woodgate, 1999). Furthermore, although interesting associations have been found between parent and child factors, most research uses correlational and cross-sectional methods, so the direction of cause-effect relationships are

unclear. In addition, the effectiveness of interventions utilizing case-studies should be explored using larger sample sizes and standardized measures. The findings from existing studies on parent influences on child outcomes should be extended using more experimental and longitudinal studies to further our knowledge about how parents can help their children with cancer cope positively with their illness and treatment. The experimental studies should include attempts to intervene at the level of the parent along with an examination of child outcomes. More importantly, the interventions should be based on existing knowledge of parent influences on child behaviors outlined above. Existing parental interventions focus on parents easing their children's short-term distress during painful procedures. Other programs focus on providing families with coping strategies without directly studying how parents can affect long-term child outcomes. Given the important influence of parents on child coping, there is a striking lack of interventions that directly involve the role of parents in affecting specific long-term adjustment outcomes in their children; this is therefore an excellent area for future study.

School

While young patients spend much of their time with parents at home, after the initial shock of the cancer diagnosis and treatment, children must readjust themselves back into the school system. This is often a challenge (Fritz, Williams, & Amylon, 1988). In one study of 239 patients with pediatric cancer, patients missed an average of 43 school days the first year of their diagnosis, and two years later, patients still missed an average of 21 days (Lansky, Cairns, & Zwartjes, 1983). School is often missed due to medical treatments or illness status, but absences may also be related to patients' fears of being rejected by schoolmates and fears that overprotective parents have for their children

(Chekryn, Deegan, & Reid, 1986; Katz & Jay, 1984; Klopovich, Vats, Butterfield, Cairns, & Lansky, 1981; Lansky, List, & Ritter-Sterr, 1986). It is estimated that about 11% of pediatric oncology patients suffer from school phobia, which is much higher than the 1.7% prevalence reported in the population at large (Lansky, Lowman, Vats, & Gyulay, 1975). Given the difficulties that children encounter during school reentry, it would be important to learn more about what can ease this transition.

Alternative Schooling Options

Young patients may enroll in homebound or hospital schooling during their treatment (Searle, Askins, & Bleyer, in press). During the initiation of cancer treatment, the majority of patients start homebound schooling to keep up with their schoolwork (Baysinger, Heiney, Creed, & Ettinger, 1993). One study compared patients with cancer who were homebound to those who were school educated and found that those who studied at home had significantly lower emotional stability and social competence than those who went to mainstream schools (Bessel, 2001). Patients in homebound schooling often feel unprepared to return to their community schools and report feeling lonely and isolated (Bessel, 2001; Searle et al., in press).

Some adolescent patients in hospital-based schooling in the United Kingdom also reported being behind when returning to their mainstream schools. They were also dissatisfied because they felt that the hospital school room was tailored for younger children (Glasson, 1995). Adolescents in another study reported that while they avoided discussing cancer-related issues with others in their hospital-based class, it was helpful to interact with peers who shared similar experiences. Moreover, a subgroup of these adolescents (who were not academic high achievers prior to their

diagnosis) reported feeling a greater sense of confidence and academic achievement. This may have been due to the individualized attention and enrichment courses provided by the hospital school (Searle et al., in press).

Although there can be benefits to alternative schooling for some patients, studies suggest that parents should encourage their children to remain integrated in traditional schools if possible. The prompt return to school is thought to be important for patients' social adjustment because it provides opportunities for social support from teachers and schoolmates, and exposes patients to "socialization processes typically experienced by school-aged children" (DuHamel, Redd, & Johnson Vickberg, 1999, p. 725). Patients themselves have also reported that the return to school had a normalizing effect on them (Chekryn et al., 1986).

Sources of Distress in School Settings

The transition back to mainstream schools may also be challenging. In one interview study of 45 survivors of Hodgkin's disease, 40% reported unpleasant experiences when they returned to their schools, including being teased about baldness and being excluded by those who thought they were "contagious" (Wasserman, Thompson, Wilimas, & Fairclough, 1987). Some patients also worried about their absences and how they would be able to incorporate themselves back into their friendship networks (Chekryn et al., 1986). Other patients mentioned that it would be helpful to have more information about how to talk to classmates about cancer, and that practicing or role playing before returning to school would be beneficial (Orr, Hoffmans, & Bennetts, 1984).

Despite the difficulties that students with cancer face at school, it appears that relationships with classmates mitigate the negative experiences. This is consistent with theories on the positive effects of social support (Cohen & Willis, 1985). One study of 30 newly diagnosed children with cancer aged 8-13 found a strong and consistent relationship between patient adjustment and support from classmates. That is, patients with higher perceived support from classmates were less depressed, less anxious, had higher self-esteem, and fewer externalizing behaviors than patients with lower perceived support from classmates. Perceived support from parents, teachers, and friends were not as strongly related to outcomes (Varni, Katz, Colegrove, & Dolgin, 1994).

In sum, preliminary evidence suggests that adjustment at school among young patients with cancer may be enhanced by encouraging patients to attend normal schools if possible, and by implementing cancer education programs that encourage positive relationships with their classmates. These actions may serve to reduce their isolation and reduce misconceptions and teasing by classmates by increasing awareness of issues related to cancer. In the next section, we review interventions that have been conducted to address problems that young children with cancer may face at school.

School Reintegration Intervention Programs

Several studies have quantitatively evaluated the effectiveness of programs developed to enhance patients' adjustment to schooling following their diagnosis (e.g., Benner & Marlow, 1991). One multifaceted intervention to help students with cancer adjust to school reentry involved meetings

with the patient's family, conferences with school personnel, and classroom presentations to teach students about the patient's illness and needs. Hospital-based psychologists later made follow-up contact to strengthen communication between the family, the medical team, and the school. Following the intervention, patients exhibited significantly lower levels of anxiety, depression, and behavioral problems, and significantly greater social competence (Katz, Rubinstein, Hubert, & Blew, 1988).

There is some evidence, however, that the effects of these interventions may not be enduring. In another intervention, elementary school classmates of children with cancer were presented with information about cancer (general prognosis, treatment, side effects, etc.) and participated in discussions about feelings frequently experienced by children with cancer. Immediately after the intervention, schoolmates' knowledge about cancer increased, their fears about cancer decreased, and their desire to socially interact with their classmate with cancer increased. However, in a one-month follow-up, while the classmates retained knowledge of cancer and their fears about cancer remained low, their desire to interact with the cancer patient had decreased (Treiber, Schramm, & Mabe, 1986).

Other research on school reintegration programs provides anecdotal evidence of their effectiveness. The interventions often aim to improve the relationship of patients and their classmates by providing the latter with information about the disease (e.g., Baysinger et al., 1993; Sachs, 1980). Some interventions include school personnel. In one such intervention, a clinical nurse met with school personnel to clarify the patient's diagnosis, treatment, and special needs. The nurse later met with the patient's classmates to provide information about cancer and

what they could do to be a “good friend.” Post-intervention interviews revealed that patients found it helpful for their classmates to learn about their disease (McCarthy, Williams, & Plumer, 1998). In another intervention conducted in Italy, teachers of children with leukemia were provided general information about the illness and were encouraged to individually devise plans to facilitate the leukemia patients’ acceptance in class (Deasy-Spinetta, 1993). One fifth grade teacher developed a year-long science project in which each student conducted age-appropriate research on blood and wrote about their personal reactions to their classmate’s diagnosis. The research and essays were then printed and sold throughout the school. As a result, classmates learned about leukemia, they were able to express themselves about the disease, information about leukemia was disseminated throughout the school, and the researchers felt that the patient was fully integrated into the class. While studies such as these provide only anecdotal evidence, it might be fruitful to evaluate these promising approaches to school integration with stricter research methods to test for generalizability and to confirm their efficacy so that others may benefit from their implementation.

Future Directions for Research on Schools

Given the difficulties that children with cancer can face in re-entering school (school phobia, teasing, etc.), support should be available during this transition. While the causes of difficulties patients face when they are schooled at home or in the hospital are not clear, the existing evidence indicates that attempts should be made to integrate the child into traditional schooling environments. When patients attend regular school, the studies we reviewed strongly suggested that interventions should focus on encouraging positive relationships with classmates. Attempts

should be made to insure that the effects of the intervention are enduring and that the interventions meet the needs of the children themselves.

Although existing studies on school intervention programs are promising, most research on school interventions provide only anecdotal evidence. While qualitative studies provide some insight, in order to further generalize the findings, these case studies should be extended to include larger samples and control groups in more quantitative, rigorous research designs. These empirical studies would help clarify causal effects of multi-component interventions to identify what components are most effective in the short as well as long term. Larger studies that include more patients would allow for an investigation of stable effects such as type of schools (e.g. class size, private vs. public) and patient demographic or treatment characteristics on the success of school reentry programs.

Peers/Friends

Just as classmates have an influence on the adjustment of young patients following diagnosis, their close friends and peers also play important roles in their lives. A small pilot study of six young patients with cancer revealed that those who scored higher on a measure of peer attachment tended to have higher levels of hope than those who were more isolated from friends (Saba, 1991). In fact, friends are frequently nominated by young patients with cancer as one of their greatest sources of support (Kyngas et al., 2001; Ritchie, 2001). However, it is often difficult for patients to obtain the support of their friends when they need it the most, after their diagnosis and treatment. Teachers have reported that young patients with cancer had fewer

friends than healthy counterparts and participated less in playground activities (Deasy-Spinetta, 1981). Adolescents with cancer also report a reduced number of friends following diagnosis (Enskar, Carlsson, Golsater, & Hamrin, 1997) and have an average social network size that is much smaller than that of healthy teens (Nichols, 1995). The impact that cancer can have on the patient's network of peers can be enduring. Survivors of pediatric cancer tend to have fewer mutual friends and experience more social isolation than their healthy peers (Noll, Bukowski, Davies, Koontz, & Kulkarni, 1993; Vannatta, Gartstein, Short, & Noll, 1998).

In addition to support from healthy peers, young patients with cancer may also receive helpful support from their peers with cancer (Dunsmore & Quine, 1995; Hockenberry-Eaton & Minick, 1994). Adolescents with cancer often feel that their healthy friends often do not know how to be supportive with issues related to cancer treatment (Nichols, 1995). Teens have indicated that they want to connect with other teens with cancer to help them through developmental tasks, as well to exchange information about various cancers, procedures, and treatments (Bluebond-Langner, Perkel, & Goertzel, 1991; Enskar et al., 1997). In fact, when talking about the feelings behind having their disease, adolescents with cancer preferred to gain support from other teens with cancer even more than from family members or friends (Dunsmore & Quine, 1995).

Peer Interventions

Healthy peers. In order to improve peer relations for children and teens with cancer, a variety of interventions have been developed. In one preliminary study of an intervention (Varni, Katz, Colegrove, & Dolgin, 1993), 64 newly diagnosed children between the ages of 5 to 13 who all

received routine school reintegration services were randomly assigned to an experimental treatment group that received supplemental social skills training or to a standard treatment control group. As part of the social skills training intervention, patients were given training in social-cognitive problem-solving (brainstorming solutions to resolve cancer-related interpersonal problems), assertiveness (expressing feelings and concerns to others), and coping with teasing (strategies such as stopping inappropriate comments through lack of behavioral response). In six- and nine-month follow-ups, patients who received social skills training showed improvements in anxiety and self-esteem and their parents reported reductions in problem behaviors as well. Patients in the standard treatment control group did not show improvements on any of the measures used in this study. This study suggests that giving patients skills to manage their relationships with peers in combination with routine school reintegration programs may be more effective than the standard program alone.

One small intervention program involved bringing eight young people with cancer or other hematological diseases together with 20 healthy peers once a month for two years (Clark et al., 1992). While the group at first discussed information about cancer, as the meetings progressed, they spent more time discussing school, future plans, and other topics of mutual interest. After two years, almost all of the cancer participants felt that the group helped them to cope with social aspects of their illness, to decrease anxieties about talking about their illness, and to feel better about themselves. Many also reported that they developed at least one friendship with a healthy group member as a result of their participation, and the healthy participants reported that their attitudes toward teens with chronic disease improved. While these results are positive, they are

only suggestive and should be interpreted with caution due to the methodological limitations of the study.

Peers with cancer. Currently, there are many organizations available for chronically ill patients to meet one another in face-to-face support groups, online groups, and camps (e.g., Brokstein, Cohen, & Walco, 2002; Finn, 1995; Johnson, Ravert, & Everton, 2001; Swenson, 1988). A study of one camp for children with cancer called Camp Can-Do revealed that camp members liked interacting with peers without feeling self-conscious about cancer side-effects, and appreciated the understanding and empathy that they received from camp members. Furthermore, some of the children counted their camp friends among their best friends, and a six-month follow up revealed that about half stayed in touch through letters and phone calls (Bluebond-Langner et al., 1991). Thus, helping children to make connections with other children who are ill facilitates an additional form of peer support that can be helpful given their unique situation.

Future Directions for Research on Peers

Future research on the role of peers should consider the effects of individual patient characteristics such as physical appearance, health status, and number of days missed from school, all of which may affect peer friendships (Benner & Marlow, 1991). Studies can also be designed to compare the nature and frequency of support received from healthy peers vs. peers with cancer. In addition, existing instruments measuring social support networks should be adjusted to accommodate cancer-specific sources of support, such as support from health professionals and peers with cancer (Woodgate, 1999). Finally, because the effects of

interventions with peers (as with any intervention) can be short-lived, effort should be taken to include long-term follow-ups of intervention efficacy in evaluation studies, and to develop interventions that are designed to have enduring effects.

Technology

There is ample evidence that the relationships that pediatric patients with cancer have with their parents, teachers, schoolmates, and peers are all important and provide fruitful areas for intervention to promote patient psychosocial adjustment. In the previous sections, examples of those interventions were reviewed. More recently, however, new tools for aiding patient support have been developed with the advent of computer-driven interactive technologies such as video games, CD-ROMs, and the Internet. These new technologies provide a unique opportunity to tap into the natural interests of today's young people raised on computers, MTV, and high-speed video games (Prensky, 2000). Indeed, they may be ideal vehicles of intervention for the current cohort of young people raised to think "digitally."

Video Games and Educational Software

For cancer. The first studies of interactive media and child cancer support utilized simple video games. These games were mainly used as distractions during painful treatment procedures (Kolko & Rickard-Figueroa, 1985; Macner-Licht, Rajalingam, & Bernard-Opitz, 1998; Sander Wint, Eshelman, Steele, & Guzzetta, 2002; Schneider & Workman, 2000). These initial uses for

video games have since been followed by computer-assisted instructional intervention programs developed to provide health-related information in addition to entertainment and distraction.

One of the first cancer-based computer programs was a simple 2-D program called, What Are Blood Counts? It was designed to be a computer-assisted instructional intervention to teach children about blood cells and to prepare them for possible side effects related to their chemotherapy treatment (Peterson, 1996). The program presented information about blood cells, bone marrow, and platelets with interactive text and graphics. A questionnaire study revealed that children's knowledge about blood significantly increased after playing the game (Peterson, 1996).

More recently, an interactive CD-ROM called Kidz with Leukemia: A Space Adventure was developed to educate young patients with leukemia about their disease and its treatment. It allowed users to learn in an interactive environment through the use of puzzles and games in addition to animations and videos (Dragone, Bush, Jones, Bearison, & Kamani, 2002). In this environment, players could explore the planet "Leukator" and visit places such as "The Testing Center," where they could learn about spinal taps and radiology tests, and the "The Get Better Place," where users could learn about nutrition, preventing infections, and relaxation techniques. An evaluation of this program showed that compared to a control group who read a book on leukemia, those who used the CD-ROM had an increased feeling of control over their health. There were no differences between the groups in children's knowledge of events associated with leukemia.

Cancer-related CD-ROMs have also been developed for adults. Using Breast Cancer Lighthouse, patients can take a virtual walk along the beach and stop to hear personal stories of women who have survived breast cancer. A second CD-ROM, Easing Cancer Pain, takes place around a virtual campfire where participants can listen to people tell stories about their pain management. Researchers believe that software such as these can serve as a “virtual support groups” (Greene & Heeter, 1998). Similar support group software could be developed for adolescent and young adult patients in pediatric oncology. Also, parents may find this virtual method of intervention useful to access peer support when designed specifically for their needs.

Cancer-related CD-ROMs also have been developed for healthy populations as a tool to prevent cancer. Playing It Safe in the Sun is a CD-ROM in which three cartoon characters illustrate extremely protective, extremely risky, and appropriate sun-behaviors. This program has been used in elementary schools to provide teachers with an effective and accessible tool for instructing students on sun safety and risks for skin cancer. Students who used the CD-ROM had greater post-intervention knowledge about skin cancer than did students who were provided standard cancer information from their teachers (Hornung et al., 2000).

For children with other illnesses. Other disease-specific CD-ROMs in a video game format show promising results (e. g., Homer et al., 2000; Lieberman, 2001; Rubin et al., 1986). Packy & Marlon was developed as a video game for young patients with juvenile-onset diabetes (Brown et al., 1997). In this game, players were required to help their characters monitor their blood glucose, take their insulin, eat balanced foods, etc. In a study with 59 patients with juvenile diabetes aged 8 to 16, researchers found that compared to a control group that played a non-

medical video game, those who used the Packy & Marlon game showed improved communication with their parents about diabetes and significant health-related behavior changes. However, measures of self-efficacy for diabetes self-care, knowledge about diabetes, urgent visits to hospitals, and blood glucose levels showed no differences as compared to controls.

The Internet

The Internet, another area of technology that has seen an explosion of usage, may be a way for patients with cancer to obtain information and support through websites as well as online communication platforms. Use of the Internet is widespread among young people. A study of 412 10th graders from diverse socio-economic backgrounds found that 96% had used the Internet, and 74% used it at least twice a week (Borzekowski & Rickert, 2001a). Many of these adolescents are also accessing the Internet for health care information. Forty-two percent of the 319 youths in one study had tried to get health information on the Internet, and among those teens, half had tried to get information on specific diseases such as cancer, heart disease, and STDs (Borzekowski & Rickert, 2001b).

Websites. By logging on to the World Wide Web, patients with cancer can access a wealth of information about cancer from sources such as national cancer organizations, voluntary associations, and personal websites created by individuals with cancer (Cotterill, 2001). Websites are being increasingly used as sources of health information and support. A study of 191 adult patients with cancer revealed that a majority searched for information about their illness, with the Internet being the most popular search medium (Chen & Siu, 2001). Another survey from a

cancer-related website revealed that most users of the site believed that information from the Internet helped them to cope better with cancer (Ehrenberger, 2001).

The Internet may be a particularly appropriate mode of intervention for adolescents with cancer. It can provide information to young people who feel frustrated by restricted access to health care resources or who feel anxious about asking sensitive health questions (Borzekowski & Rickert, 2001a). It can also help youths to be more self-reliant in coping with their illness. In an interview study of 14 adolescents with cancer, patients indicated that they wanted to cope with their disease as independently as possible and they felt that searching for information (through books, magazines, and the Internet) was a good coping strategy that they could do on their own (Kyngas et al., 2001).

Online support groups. While it is clear that the Internet can be a valuable source of information, it can also be a source of social support. Bulletin boards, newsgroups, listservs, and chatrooms are now being used by people with cancer to find each other online and offer advice and peer support (Sharp, 2000). (Bulletin boards and newsgroups are online platforms where users can post, read and respond to text messages on particular topics; listservs are address lists for distributing mass emails on particular topics; and chatrooms are online communication systems that allow users to exchange text messages with “virtual” room members in real time (Subrahmanyam, Kraut, Greenfield, & Gross, 2000)). In one study of 37 online support groups (newsgroups and bulletin boards) for 20 different diseases researchers found that cancer groups received the most postings out of all the online disease support groups studied (Davison, Pennebaker, & Dickerson, 2000). Some websites (e.g., www.squirreltales.com and

www.candlelighters.com) allow parents of children with cancer to communicate with each other via chatrooms and bulletin boards. Furthermore, Internet portals (e.g., Yahoo! and AOL) provide cancer-specific chatroom sessions for patients and loved ones to communicate online.

Although there are no studies of online support groups for adolescents with cancer, research on teens with cystic fibrosis suggests that they can aid adjustment. In one study, an online bulletin board was developed to connect teens with cystic fibrosis (Johnson et al., 2001). Using this bulletin board, teens posted 588 bulletin board messages in five months and sent emails to one another. Follow-up surveys showed an increase in teens' perceptions about the number of friends that they could relate to who had CF. However, their outcomes did not improve in other domains.

An Online Computer Network

In the sections above, we discussed how new advances in technology could provide support for chronically ill children and their families. Video games can be used for distraction, CD-ROMs can provide information and support, websites can be surfed for information, and online support groups and bulletin boards can provide contact with peers. These are all disparate sources of support, but STARBRIGHT World (SBW) is one comprehensive program that combines multiple elements into one system. SBW is a broadband, online computer network that connects children with chronic or serious illnesses in over 95 hospitals throughout the U.S. and Canada (Bush, Huchital, & Simonian, 2002). SBW includes a variety of elements where patients can find distraction (e.g., games, drawing, and writing activities), disease specific activities (e.g., links to

relevant sites, chatting with patients with similar illnesses), important information (e.g., multimedia programs on health care, ask a doctor chats), and social support (e.g., chatrooms, instant messaging, video conferencing, bulletin boards) (Bush et al., 2002).

Research on SBW has shown some evidence of psychosocial benefits. In one study (Holden, Bearison, Rode, Kapiloff, & Roseberg, 2000), 44 chronically ill patients between the ages of 7 and 18 were assigned to alternating conditions of using SBW or participating in general activities (playroom activities, visiting with family and friends, watching TV, etc.) for 30-minute periods (Holden et al., 2000). During each 30-minute session, subjects rated their pain intensity, pain aversiveness, and anxiety. Results revealed that children reported significantly lower degrees of pain intensity, pain aversiveness, and anxiety when using SBW than when they participated in general activities.

Other Technologies

Advances in technology and the imagination of toy designers are expanding ways in which one could use interactive media to help children with cancer. For example, virtual reality headsets have been used to play commercially available games or to watch 3-D videos in stereo sound as distractions for older children with cancer during unpleasant procedures (Sander Wint et al., 2002; Schneider & Workman, 2000).

Plush characters that have speaking capabilities via an internal audio device have been developed to help younger children with serious illnesses. One type of animated doll, called STARBRIGHT

Hospital Pals, narrates stories and offer words of encouragement to children undergoing radiation therapy (Bush et al., 2002). Researchers at M.I.T. developed SAGE (Storytelling Agent Generation Environment), a stuffed bunny with the capacity to engage patients in interactive conversations about their treatments for cardiac disease and respond directly to their comments (Bers, Gonzales-Heydrich, & DeMaso, 2002). With this unique toy, patients have the ability to create their own characters and to program original stories into SAGE to be shared with their peers.

Multi-user domains (MUDs) are also being developed to allow chronically ill youth to interact with one another. MUDs are real-time, online communication systems that have an added capacity for role-playing games (Subrahmanyam et al., 2000). Using a MUD program called Zora, patients with renal disease were given an opportunity to build 3-D virtual rooms and populate them with objects and characters representing themselves (Bers et al., 2002). With Zora, patients on dialysis could communicate with one another in real time via text or gestures, or they could use the bulletin board to post messages to one another. They could also explore each other's 3-D virtual communities. Patients reported that Zora helped them to make more friends and to make them feel more part of a group while on dialysis. These and many other innovations in technology could be used to increase peer interactions in pediatric cancer populations.

Advantages and Disadvantages of Technology

Because the use of interactive technology in pediatric oncology is relatively new, we would like to highlight some of the advantages and disadvantages of its use. To begin with advantages, a video game format, such as that often used in computer assisted learning, allows children to have a sense of autonomy as they independently maneuver through the environment, and the use of animation and voice-overs allows even children with limited literacy to play (Dragone et al., 2002). Software programs with this format also sustain children's attention and provide immediate, individualized feedback (Lepper & Malone, 1987). Disease-related interactive games may also provide an excellent opportunity for patients to receive feedback on health choices, to rehearse self-care skills, and to access information about their illnesses in a fun context (Lieberman, 2001). In addition, the social nature of video game play encourages discussions with parents, teachers, and peers about health-related topics found in the games (Lieberman, 2001).

The Internet also provides an excellent opportunity for youths with cancer to communicate with each other. Online groups offer anonymous, 24 hour access to those whose debilitating physical condition, personal distress, or geographical isolation may make attendance at face-to-face support groups difficult (Finn, 1995; Johnson et al., 2001; White & Dorman, 2001). Gender differences are also minimized in an online format. One study of a health-related bulletin board group found a lack of gender differences in the frequency and content of postings (Salem, Bogat, & Reid, 1997). Furthermore, participants in online support groups for adults appear to readily give and receive support and advice from their online acquaintances (Klemm, Reppert, & Visich, 1998; Salem et al., 1997); the same may be the case for young patients with cancer.

These new technologies may also have negative aspects. While the Internet can connect people from diverse locations, without visual and aural cues, this connection lacks the personal touch of meeting someone face to face (White & Dorman, 2001). Researchers have found that greater use of the Internet was associated with significant declines in social involvement, as well as increases in loneliness and depression (Kraut et al., 1998). However, these negative effects dissipated in a 3-year follow up study (Kraut et al., 2002). Health information on the Internet is also not always accurate (Biermann, Golladay, Greenfield, & Baker, 1999; Eysenbach, Powell, Kuss, & Sa, 2002). Furthermore, finding websites specifically designed for children with cancer can be time consuming. The use of CD-ROMs and computer networks could also be problematic in that not all patients have ready access to personal computers, and patients may be unaware of available cancer-specific games. Nurses, physicians, social workers, teachers, and parents should therefore be better informed about the latest research on psychosocial support as well as the available technologies that can aid in cancer support for young people.

Future Directions for Research on Technology

The use of computer technology provides a variety of ways to support patients with pediatric cancer through instructional CD-ROMs, video games, websites, computer networks, online support groups, and even interactive plush toys. Future research should clarify the strengths of the technologies in different domains. For example, while it is clear that video games provide a good source of distraction, it is not clear if they are ideal media for improving health behaviors. More research is needed on the benefits of the use of these technologies. For example, while there is evidence that children with cancer and their parents go online for information and

support, there is very little empirical evidence available about how much this activity benefits them, and if the people who could benefit the most from it have access to it. Comparison of online and face-to-face support groups for young people can also be researched. Future studies should also investigate the content in bulletin boards and chat rooms to explore patients' attempts to support and be supported in an anonymous setting.

Conclusions

It is clear that the psychosocial support provided to young patients with cancer by parents, teachers, schoolmates, and peers is indeed important, and a variety of interventions are available to improve interpersonal interactions and coping. Very few attempts have been made to improve the psychosocial adjustment of patients through their parents. Most psychosocial interventions tend to focus on aiding patient coping by increasing communication about cancer, teaching peers and classmates about cancer, and providing patients with peer support via cancer camps and support groups. The use of technology has provided new forms of support in each of these domains. Parents can access the latest cancer information on the Internet, and parent support groups are also available online. Video games can also be used to initiate parent-child conversations about cancer, or they can be requested to alleviate child distress during procedures. Schools can use computer games and websites to teach classmates about cancer, and email can link hospital-bound patients with their teachers and friends. Peer relations can also be improved through contact with other via bulletin boards, chatrooms, and listservs. Online computer networks such as STARBRIGHT World can connect children in hospitals throughout the country with each other. With the variety of available interventions, nurses and others in the medical

profession can play an important role in increasing the awareness of and access to different forms of psychosocial support for young patients with cancer and their families.

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