

Physical Disabilities: Education and Related Services, 2015, 34(2), 1-13.
doi: 10.14434/pders.v34i2.19643
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PDERS

ISSN: 2372-451X

<http://scholarworks.iu.edu/journals/index.php/pders/index>



Promising Practice

STUDENTS WITH PEDIATRIC CANCER: A PRESCRIPTION FOR SCHOOL SUCCESS

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Abstract: Due to medical advances, many students with acute chronic illnesses, like pediatric cancer, are able to attend school. The professional literature reflects the need for reform of educational strategies for children facing cancer treatment and who will be absent for extended periods of time. In order to promote successful educational services and the reintegration of students into school, it is vital for multidisciplinary teams and families to collaborate effectively. This article provides a plan to promote successful integration of students with cancer within regular classrooms.

Keywords: *pediatric cancer; collaboration; homebound instruction; differentiated instruction*

Introduction

Daniel is a nine-year-old boy who enjoys playing Nintendo with his family and soccer with his friends. He is talented on the soccer field. At school he likes math and science, but is not fond of his language arts lessons. Overall, he is a typical nine-year-old boy. One day Daniel fell while playing soccer, which caused bruises on his leg. As time passed, his parents noticed a hard, painless lump on his neck, continued bruising, and fatigue. His parents attributed the symptoms to his rough and tumble soccer playing. Eventually, his parents decided to take Daniel to their family doctor.

After a battery of tests, Daniel was referred to an oncologist, who diagnosed Daniel's condition as Neuroblastoma, a rare form of cancer. This diagnosis resulted in a protocol that would require Daniel to miss school for several months, to undergo chemotherapy and radiation. Along with medical personnel, Daniel's concerned parents immediately went to his school to meet with his classroom teacher, school psychologist, school counselor, the school nurse, principal, homebound teacher, child life specialist, and hospital oncology nurse. Together they created successful education and health plans, which required his teachers, medical personnel, and parents to work closely together to ensure Daniel could continue his fourth-grade education without missing a beat. Using Skype, telephone calls, visits, and cards, Daniel remained close with his classmates, avoiding the feeling of isolation upon returning to school. This young boy's story is the exception not the norm. The literature suggests that there are few courses of action in place for parents, teachers, and administrators to follow when dealing with a child with cancer. This article suggests a plan to assist school personnel in meeting the needs of students like Daniel.

Overview of Pediatric Cancer

At this time, pediatric cancer is the leading cause of death by disease in children from infancy to age 15 in the United States. In 2008, there were approximately 10,730 children diagnosed with cancer (National Cancer Institute [NCI], 2008). Major types of childhood cancer include leukemia (30%), brain and nervous system (22.3%), neuroblastoma (7.3%), Wilms tumor (5.6%), Non-Hodgkin lymphoma (4.5%), rhabdomyosarcoma (3.1%), osteosarcoma (2.4%), and Ewing sarcoma (1.4%). Despite a slight increase in the diagnosis of invasive cancer in children in the past 30 years, the combined 5-year survival rate for all pediatric cancers has improved from less than 50% in the 1970s to 80% today (American Cancer Society, 2007). Due to the advancements of pediatric oncology, biomedical science, and medical technology what was once often a fatal condition for many children, pediatric cancer has evolved into a chronic illness, "... an illness that has no cure, but is not necessarily terminal" (Kaffenberger, 2006, p. 380). Approximately 20% of children have a chronic illness, like cancer, and it is critical to note that approximately one-third of children with chronic illnesses experience consequences severe enough to interfere with school function and performance (Kaffenberger, 2006; Shaw & McCabe, 2008).

The diagnosis and treatment of pediatric cancer has both short- and long-term impacts on children and their families. Cancer affects a child's physical, psychological, and academic development (Brown, Bolen, Brinkman, Carreiri, & Cole, 2011; Prevatt, Heffer, & Lowe, 2000;

Vance & Eiser, 2001). Many pediatric cancer survivors develop cognitive impairments and learning difficulties, have extensive school absences, and experience diminished academic performance, which affects the child's desire to return to school and ability to be successful in school (Brown et al., 2011).

It is important for educators, along with health care workers, to address concerns such as a child's quality of life, psychosocial and cognitive development, and the family's challenges of dealing with complicated treatment options for their child (Bessell, 2001; Searle, Askins, & Bleyer, 2003). At this time, quality of life issues, like a child's education, have not been sufficiently addressed in the professional literature (Irwin & Elam, 2011). It is important for teachers and school personnel to recognize that they are in the position to positively impact a child's quality of life by working together to develop comprehensive and flexible educational and health plans for a child undergoing cancer treatment. School personnel should keep in mind that after cancer treatment has been completed, a child may continue to struggle with short- and long-term cognitive difficulties, as well as emotional, social, and behavioral challenges (Irwin & Elam, 2011). Prevatt et al. (2000) noted that "Although not empirically documented, there is clinical consensus that a sense of normalcy can be very beneficial in facilitating adjustment of the ill child, and that returning to school is one of the best ways to ensure this normalcy" (pp. 461-462).

An extensive review of the literature did not reveal any one policy or procedure for continuing education while providing for a child with cancer. However, the literature did suggest the role of the classroom teacher in the education of a child with cancer cannot be underestimated (Brown et al., 2011; Shiu, 2001; Taras & Potts-Datema, 2005). This being said, the general education teacher is usually not trained to academically address or emotionally handle such a challenging role or to develop an academic plan for a child with cancer (Brown et al., 2011). The American Academy of Pediatrics (2009) calls for school personnel to receive additional education about students with chronic conditions and related health care management (Hopkins & Hughes, 2015).

Relevant Laws & Services

Many teachers will provide services to a child with cancer at some point in their teaching careers (Huffman, Fontaine, & Price, 2003). Unfortunately, educational training programs and policies for pre-service and in-service teachers have not been sufficiently developed to meet the needs of students with cancer (Irwin & Elam, 2011). Despite mandates of federal laws, like the Individuals with Disabilities Education Improvement Act (IDEA, 2004) and Section 504 of the Rehabilitation Act of 1973, to provide reasonable accommodations for students with disabilities in the least restrictive environment, children with cancer do not clearly fit into existing programs. IDEA's category of "other health impairment" is "restrictive as it requires a child to be actively experiencing '...limited strength, vitality, or alertness due to chronic or acute health problems' and this lack of vigor must adversely affect the child's educational performance. This definition is not comprehensive in that children who are chronically ill can experience multiple issues related to their illness that interfere with school that may or may not be rooted in vivacity" (Irwin & Elam, 2011, p. 69).

Unlike IDEA, Section 504 of the Rehabilitation Act of 1973 is not specifically a school law, but more of a civil rights law, which provides for students whose disabilities do not fit under existing IDEA disability definitions. Using a categorical approach to disability, Section 504 protects students with conditions like communicable diseases; temporary disabilities from accidents; and asthma, allergy, and environmental illnesses. The Section 504 guidelines provide for equal protection from discrimination in school, employment, social, and health settings (McClesky, Rosenberg, & Westling, 2013).

This being the case, many students with cancer do not meet the criteria for existing programs and are, therefore, ineligible for program funding (Irwin & Elam, 2011; Thies, 1999). Additionally, with the push to meet the No Child Left Behind (NCLB) Adequate Yearly Progress (AYP) attendance expectation of 92%, some schools have been known to withdraw students who are chronically ill, further impacting their quality of life by isolating them from their peers and leaving families to contemplate options like home schooling (Bessell, 2001; Irwin & Elam, 2011). “Under Section 504, a chronic illness can be categorized as a disability, consequently providing individuals with chronic illness protection from discrimination. Yet many children suffering from chronic illness are being withdrawn from school due to their inability to attend school on a regular basis. School districts do not withdraw students with learning disabilities as a result of their disabling condition; therefore it should be unacceptable to withdraw children suffering from an illness” (Irwin & Elam, 2011, p. 71).

Due to inadequacies in current laws, schools and healthcare systems are left to interpret existing guidelines and policies when developing educational and healthcare plans for a student with cancer (Hopkins & Hughes, 2015; Irwin & Elam, 2011; Thies, 1999). The needs of a child with cancer are different from other students and their needs will likely not be classified in the same manner as those of children whose characteristics and assessment data meet the criteria for other established disability classifications (Bessell, 2001). Students with cancer need support so that they do not fall between the cracks of educational and health systems that are not well connected. It is, therefore, critical that effective, ongoing communication occurs between parents, medical, and school personnel (Brown et al., 2011; Hopkins & Hughes, 2015). Typically, the school nurse, if one exists, is left to handle health issues while the classroom teacher is left to focus on a child’s education (Thies, 1999).

It is, therefore, imperative for schools to be prepared to best meet the needs of a student with cancer by creating a multidisciplinary team to collaborate and develop an Individualized Education Program (IEP) for children whose educational performance is significantly impacted and who will need special education services. If the child’s educational performance is not adversely affected by their medical condition, a 504 plan can be created to ensure that the child receives an appropriate education as well as equal access to educational services (Irwin & Elam, 2011). Additionally, in close collaboration with the family and the child’s medical team, the school nurse should oversee the development of an Individualized Health Plan, a plan collaboratively developed by school nurses, teachers, and other school personnel (e.g., nutritionist, physical therapist, occupational therapist), which provides up to date information about the child’s medical condition, case managers, daily treatments, monitoring responsibilities, emergency procedures, and additional accommodations such as school and classroom access, changes in instruction and activities (e.g., rest breaks, changes in length of activities) and

assistive technology (DaPaepe, Garrison-Kane, & Doelling, 2002). Finally, the National Association of School Nurses (NASN, 2015) recommends that the team consider developing and implementing an Emergency Care Plan that specifies how to handle a medical emergency while at school. It may be necessary to develop a combination of two or more of the educational and health care plans in order to comprehensively address the academic, social, emotional, and physical needs of a child living with cancer (Clay, Cortina, Harper, Cocco, & Drotar, 2004; Hopkins & Hughes, 2015; Kaffenberger, 2006; Thies, 1999).

Multidisciplinary Team Approach

Due to long-term side effects (e.g., cognitive problems due to chemotherapy, behavioral challenges, and language problems) of his treatment, Daniel's multidisciplinary team, including the principal, school psychologist, guidance counselor, school nurse, classroom teacher, homebound teacher, child life specialist, hospital oncology nurse, and parents, met to reevaluate Daniel's academic, medical, and social needs. The team determined that Daniel would benefit from an IEP to meet his academic and social needs and an Individualized Health Plan and Emergency Care Plan to address his health care needs upon re-entry into the classroom.

Schools should designate an individual, oftentimes the school psychologist, as a point of contact to bring together a multidisciplinary team. Given that children with cancer often experience problems related to school functioning as well as educational development and performance, the school psychologist's role is crucial. Adhering to the eco-triadic model of consultation designed specifically for children with cancer (Shields, Heron, Rubenstein, & Katz, 1995), school psychologists can examine the interplay between home, hospital, and school settings for the child in order to facilitate the child's successful transition back into the school setting (Harris, 2009).

Along with the psychologist, the team may consist of the child with cancer (if the child is comfortable with the idea), parents and family members, school administrators, teachers, other school personnel, and medical personnel (Brown et al., 2011; Prevatt et al., 2000). The team will develop and monitor flexible educational and health care plans for the child (Bessell, 2001; Clay et al., 2004). The multidisciplinary team will determine the optimal setting for educational instruction such as home schooling, homebound instruction, or use of a certified hospital teacher (Friend & Bursuck, 2015). Some suggested school and classroom strategies to consider are differentiated instruction, shortened class or homework assignments, copies of class notes, flexible school days, and strategies to promote child autonomy and to address affective issues (Friend & Bursuck, 2015; Shaw & McCabe, 2008). The designated contact person will be responsible for keeping the teacher and other multidisciplinary team members apprised of any changes in the child's educational and health progress and if any new problems arise. Figure 1 provides a suggested list of roles and responsibilities for multidisciplinary team members.

Roles and Responsibilities of Multidisciplinary Team Members

The Child with Cancer

1. Express desire to share information about illness with classmates or other peers.
2. Express further interests in social, athletic, and extracurricular activities.
3. Express concerns such as hair loss, body image, and fear of infection (Prevatt et al., 2000).

Parents and Family Members

1. Provide information about the student's evolving healthcare needs, prescribed medications, and updated emergency contact information (Students with Chronic Illnesses, 2003).
2. Provide a written description of the student's health needs at school, including authorizations for medication administration and emergency treatment signed by the student's healthcare provider (Hopkins & Hughes, 2015).
3. In order to release medical information to schools, provide health care consent in compliance with Health Insurance Portability and Accountability Act (HIPPA) regulations (Hopkins & Hughes, 2015).
4. Educate their child to develop age-appropriate self-care skills (Students with Chronic Illnesses, 2003).
5. Give written consent to share information with class peers.
6. Be aware of rights and federal legislation about the number of student absences.
7. Provide a calendar of appointments, schedules, and treatment regimens; a list of names and phone numbers of school and medical personnel; and the identification of a liaison member.

School Educational Liaison (School Psychologist or Guidance Counselor)

1. Contact parents as soon as possible after learning of a student's diagnosis (Harris, 2009; Kaffenberger, 2006).
2. Discuss school re-entry expectations (Harris, 2009; Kaffenberger, 2006).
3. Help school personnel, teachers, and classmates understand their roles in supporting the child, family, and siblings (Harris, 2009; Kaffenberger, 2006).

School Psychologist

1. Call the multidisciplinary team together to determine the student's academic, medical, social and emotional needs and determine if a full evaluation is needed (Harris, 2009). If the hospital conducted neuropsychological, physical, and occupational evaluations, the psychologist can request, with parent permission, the records for the team to review (Katz & Madan-Swain, 2006).
2. Serve as a liaison between the hospital and school to analyze child's current level of functioning within eco-triadic model of home, hospital, and school settings (Harris, 2009).
3. Oversee implementation, ongoing review, and evaluation of the child's IEP and health plans (Harris, 2009).

School Guidance Counselor

1. Provide resources and coordinate support services for the child and the child's family (Kaffenberger, 2006).

2. Determine if the child appears teased or rejected by peers. Plan and conduct a peer program for a better understanding of childhood cancer (Sullivan, Fulmer, & Zigmond, 2001).
3. Provide support to the siblings of the child undergoing cancer treatment. Siblings are often left to fend for themselves and have expressed sadness and that they felt unsupported during the family crisis (Kaffenberger, 2006).

School Health Liaison (School Nurse)

1. Serve as the coordinator of care by providing healthcare assessment, intervention, and follow-up for all children within the school setting (Council on School Health, 2008). School nursing standards are used to develop an individualized healthcare plan and emergency care plan (NASN, 2015).
2. Develop an individualized health plan and emergency care plan for the child.
3. Write and implement the emergency care plan to guide emergency procedures for school personnel (Kruger, Toker, Radjenovic, Comeaux, & Macha, 2009).

Classroom Teacher

1. Have a realistic understanding of cancer, treatments, and side effects. Assess the child's former and current academic achievement. Document effect of absences on the child's school progress. Determine if a tutor is necessary (Prevatt et al., 2000).
2. Assist with IEP development and daily lesson plans that allow for flexibility and remediate lost attendance. For academically advanced students, it is recommended that teams consider compacting the curriculum to develop academic priorities for the student (Friend & Bursuck, 2015).
3. Maintain classroom social connections by establishing ongoing peer communication and collaboration through technology, VoiceThread, Google Docs, Diigo, VGO robots, email, class blog, and letter writing (Beeman & Henderson, 2012; Bessell, 2001; Ferriter, 2009; Han, 2012; Kaffenberger, 2006; Shaw & McCabe, 2008).

School Administrator

1. Oversee that an action plan is properly implemented and necessary materials are provided (Thies, 1999).
2. Share knowledge about the school community, explain school district's special education policies and procedures, and address family's questions and concerns (Friend & Bursuck, 2015).
3. Promote normalcy and the full integration of the child into school (Spinetta et al., 2009).
4. Have a realistic understanding of cancer, treatments, and side effects (Prevatt et al., 2000) and be closely apprised about child's medical condition (Katz & Madan-Swain, 2006).
5. Ensure that curriculum and assessment standards are addressed in the child's educational plan.
6. Determine if adaptations need to be made in regards to transportation, architectural barriers, diet, medications, or activity level (Prevatt et al., 2000).

Hospital Medical Personnel

1. Hospital health care social workers arrange for at-home services when needed. Help the school counselors with the transition from the hospital back to the

- school (Claiborne & Vandenburg, 2001).
2. Hospital oncologist and oncology nurse describe possible illness-related complications that may impact educational performance (Prevatt et al., 2000).
 3. Hospital child life specialists or psychologists may be needed if the child is displaying any behavioral problems, noncompliance with treatment, or emotional symptoms such as stress, anxiety, or depression (Prevatt et al., 2000).

Figure 1. Potential roles and responsibilities for multidisciplinary team members.

School Re-Entry and Transition

As Daniel completed his final treatment, he was eager, yet nervous to return to school. At this time, he had missed several months of school and had only been able to visit his class a few times due to his compromised immune system and the risk of infection. Despite his teacher's and classmates' continued contact, through lessons over Skype, email, cards, and visits, Daniel still worried about his acceptance amongst his peers and the reactions he would have due to his changed physical appearance and decreased stamina. Previously, he had been one of the top students in the class, but now he struggled with literacy skills. He wondered if his friends would think that he was less capable than them now. His friends worried if Daniel would be strong enough to play and participate in school activities. To address his and his parent's concerns, the multidisciplinary team reconvened to develop a re-entry plan. Together they developed a child- and family-centered plan, which promoted a smooth transition back to school and positive interactions with classmates.

The multidisciplinary team members participated in training workshops that combined medical and educational personnel. These workshops lasted two days and included lectures, video presentations, discussions, and a tour of the hospital where Daniel was treated. These workshops provided knowledge for the participants about the Daniel's cancer, treatment, and the emotional impact on the child (Prevatt et al., 2000). Team members who could not participate in the face-to-face workshop could have the option to receive the same information through self-paced, computer based training modules (Brown et al., 2011).

After the training workshop, the school psychologist, the educational liaison for Daniel's case, reconvened the multidisciplinary team to review Daniel's progress and to formulate a plan for a successful re-entry to the classroom (Kaffenberger, 2006; Thies, 1999). Schools should remain flexible as multidisciplinary teams design and reevaluate individualized education programs for children based upon the student's evolving medical, academic, social, emotional and physical needs (Thies, 1999). The multidisciplinary team should carefully monitor the success of implemented strategies and determine whether methods should be continued, modified, or discontinued (Friend & Bursuck, 2015).

During the child's treatment and absence from school, the multidisciplinary team should maintain ongoing communication with the child's family and homebound or hospital teacher to monitor the child's educational progress and to make any changes to the child's educational plan.

Typically, the school psychologist will serve as the liaison and will take an active role in analyzing and evaluating the child's current level of educational functioning in order to determine the most appropriate educational and health care plans (i.e., IEP, 504 plan, individualized health plan, and/or an emergency care plan) to put in place for the student's successful re-entry into school. Most children treated for cancer will have two or more of the aforementioned plans.

Key to the success of the re-entry plan is for team members to directly and effectively communicate with the child and his family. When working with children who have special needs, it is recommended to utilize family-centered practices, an approach that is sensitive to the family's and the child's expressed needs and concerns (Sewell, 2012). To facilitate this process, it is the responsibility of schools and the medical community to provide the family information, so that they can make the best decisions for their child (Friend & Bursuck, 2015; Sewell, 2012). If the family and child feel comfortable and sense that their input is welcomed, the devised plan will likely produce better outcomes.

To further facilitate the success of the re-entry plan, teachers and school personnel need training by medical personnel and members of the multidisciplinary team. Teachers typically indicate that they lack the knowledge and training to adequately meet the needs of children with cancer (Brown et al., 2011). In a recent study, teachers were asked to rate how prepared they believed they were to handle issues when dealing with a child with cancer (e.g., classwork, homework, discipline/behavioral problems, making up missed work). The survey scale used was 1 (not at all prepared) to 4 (very prepared). The results showed 81% of the teachers rated themselves below 3 indicating that they did not feel prepared (Brown et al., 2011). In an effort to provide support and to train teachers, a group of medical personnel, including two physicians and a child life specialist, developed and piloted a collaborative self-paced, computer-based training program for teachers (Brown et al., 2011). Due to time constraints, medical personnel have typically had difficulty directly collaborating with school personnel (Brown et al., 2011). Findings from this pilot study revealed that the time commitment for medical personnel was reasonable and teachers felt better equipped to provide "more consistent, patient, understanding, and involvement with their student with cancer" (Brown et al., 2011, p. 162).

Similar to the training workshop for the educational and medical professionals, peer workshop programs should be implemented. The workshop provides a forum for healthy classmates to have their questions and misconceptions about pediatric cancer answered in order to reduce their worry and distress about childhood cancer. The program helps to foster interaction between the child with cancer and his or her peers. Peer education efforts help foster a sense of compassion for the classmate with cancer and should help eliminate the potential for bullying (Sentenac et al., 2012).

If the child's condition is terminal, it is advisable for teachers and counselors to include death education for the student's classmates (Friend & Bursuck, 2015). Classroom teachers may wish to seek assistance from a special education teacher, school guidance counselor, or social worker to develop a unit of instruction on how to meet the educational needs of the student. As a teacher, it is also important to obtain needed emotional support as you prepare yourself and your students for the potential death of a classmate (Friend & Bursuck, 2015).

Recommendations

The literature has stressed the importance of the classroom teacher's role in the education of a child with cancer (Patterson & Tullis, 2007; Shiu, 2001; Taras & Potts-Datema, 2005). However, classroom teachers are often unable to adequately deal with such a challenge on their own. This topic is rarely addressed in their pre-service and in-service training. Teachers "rate themselves as not knowledgeable about cancer and feel unprepared to manage various issues that may arise when teaching children with cancer" (Brown et al., 2011, p. 162). It is, therefore, suggested that teacher education programs include such training in their curriculum.

Inadequacies in laws and services for students with chronic illness need to be reconsidered and creative solutions for their unique needs must be determined to ensure that these students are not left behind. It is time for schools to rethink policies and procedures to ensure that best practice is in place for this unique population (Irwin & Elam, 2011). It is crucial for schools to form multidisciplinary teams that use flexible approaches when addressing the needs of children with cancer and to provide classroom teachers ongoing training and support when meeting any physical, cognitive, academic, or psychosocial needs of their students. A child's academic and social development will be fostered and the child's transition back to school will be facilitated by maintaining a child- and family-centered approach where ongoing communication and collaboration occurs between families, school personnel, and medical personnel (Bessell, 2001). By having each team member's roles and responsibilities clearly delineated, multidisciplinary teams can effectively collaborate and devise plans that provide comprehensive support for the student's medical, academic, and social needs in order to promote the student's success (Shaw & McCabe, 2008).

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