Volume 42, Issue 1
May 2024

# Research, Advocacy, and Practice for Complex and Chronic Conditions

## A Journal for Physical, Health, and Multiple Disabilities

Council for Exceptional Children | Complex and Chronic Conditions: The Division for Physical, Health and Multiple Disabilities

ISSN 2831-5723

***Research, Advocacy, and Practice for Complex and Chronic Conditions***, 2024, 42(1), pp.28–45
https://doi.org/10.14434/rapcc.v1i42.36431

Council for Exceptional Children | Complex and Chronic Conditions: The Division for Physical, Health and Multiple Disabilities

RAPCC
ISSN 2831-5723
https://scholarworks.iu.edu/journals/index.php/pders/

*Article*

# Pediatric Cancer: Promoting Desired School Outcomes Through Collaboration - A Scoping Review

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**Abstract:** *Due to medical advances, many students with pediatric cancer can attend school. The professional literature reflects the need for enhanced collaboration between medical and educational personnel to address the academic, social-emotional, and health care needs of children undergoing cancer treatment and who may experience late effects throughout their academic careers. To promote effective educational services during and after treatment, it is crucial for multidisciplinary teams and families to collaborate effectively. Additionally, preservice and in-service teachers need training and support to meet the needs of children with disabilities and chronic health conditions, like cancer.*

**Keywords:** pediatric cancer, collaboration, hospital-based school liaison, school-based liaison, school psychologist, school nurse, general education teacher

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## Pediatric Cancer: Promoting Desired School Outcomes Through Collaboration - A Scoping Review

Despite pediatric cancer being the leading cause of death by disease in children (birth to 14 years) and adolescents (15 - 19 years), the combined 5-year survival rate for all pediatric cancers has improved from less than 58% in the mid-1970s to 85% today (American Cancer Society [ACS], 2024; L'Hotta et al., 2023). In 2023, it is expected that 9,910 children and 5,280 adolescents will be diagnosed with cancer and that 1,040 children and 550 adolescents will die from the disease (National Cancer Institute [NCI], 2023). Many childhood cancer survivors will develop late effects, including but not limited to neurocognitive problems, hearing loss, memory problems, language delays, heart damage, scarring, bone fragility, delayed onset of puberty, and stunted growth (Gartin & Murdick, 2009; Northman et al., 2015; Northman et al., 2018; Children's Cancer Research Fund, 2017) from cancer treatment resulting in long-term academic, cognitive, physical, mental health, and medical challenges (L'Hotta et al., 2023; Children's Cancer Research Fund, 2022).

Approximately 20% of the school population have severe chronic health conditions (Wikel, 2023). Unfortunately, many general education teachers have not received the necessary teacher education or in-service training to prepare them to teach students with disabilities and chronic health conditions in inclusive settings (Allday et al., 2013; Kroesch & Peeples, 2021; Nabors et al., 2008) and, as a result, they feel unprepared to meet the needs of students with chronic illnesses (Irwin et al., 2018; Brown et al., 2011; Nabors et al., 2008). In this article, a plan to promote continued education, a successful transition back to school, and plans to address long-term learning, physical, and psychosocial needs that many students with cancer face will be presented.

Pediatric cancer diagnosis and treatment is associated with short and long-term impacts on a child's physical, cognitive, psychological, and academic development (Northman et al., 2015; Brown et al., 2011; Irwin & Elam, 2011; Prevatt et al., 2000; Vance & Eiser, 2011; Root et al., 2016). Many pediatric cancer survivors, especially those treated for central nervous system (CNS) cancers and leukemia, develop cognitive impairments and learning difficulties, thus having prolonged and extensive school absences, and experience declines in academic performance, which ultimately impact the child's willingness to return to and be successful in school (Trask & Peterson, 2016; Thompson et al., 2015; Brown et al., 2011).

Maintaining a child's education is a critical way to provide a sense of normalcy and help prevent the crushing isolation that many students with cancer have reported (Bessell, 2001; Spinetta et al., 2009; Gartin & Murdick, 2009). Research indicates that the needs of students with chronic health needs are not consistently addressed in public schools (Knauer et al., 2015; Selekman, 2017). Unfortunately, educational plans for children undergoing cancer treatment are often inadequate. Northman et al. (2018) reported that many childhood cancer survivors face long-term educational difficulties and are at an increased risk of being retained and receive special education services (Barrera et al., 2005; Trask & Peterson, 2016)**.** Ultimately, many cancer survivors report being alienated from their peer group (Bessell, 2001; Irwin & Elam, 2011).

With a lack of specific policies or procedures, the research strongly suggests that the classroom teacher (Brown et al., 2011; Shiu, 2001), along with the parents (Gartin & Murdick, 2009: Case-Smith, 2004; Patterson & Tullis, 2007), play pivotal roles in the education of a child with cancer. However, due to lack of preparation, the general education teacher is often not adequately equipped to provide needed support (Brown et al., 2011; Selekman, 2017; Moore et al., 2009). Irwin and Elam (2011) found the lack of knowledge and resources negatively impacted teachers' and administrators' abilities to plan and implement effective strategies for students with chronic illness. To better prepare schools for such challenges, the Council on School Health (2009) called for school personnel to receive additional education concerning students with chronic conditions and related health care management (Hopkins & Hughes, 2015). In a study of 40 teacher education programs across the country, Irwin et al. (2018) found that most programs do not require specific curriculum regarding chronic illness in children to prepare pre-service teachers. In programs where instruction is provided, instruction is often embedded in the special education program and not in coursework for pre-service teachers who will be teaching in the general education classroom where many students with chronic health needs will be served. Ultimately, the researchers found that pre-service teachers do not have direct training on how to meet the needs of students with chronic health needs and do not feel confident to meet the needs of these students in their classrooms.

Despite the success of a few in-service programs, teacher training needs to be broadly implemented for in-service and preservice teachers (Brown et al., 2011; Irwin et al., 2018). Brown et al. (2011) and Prevatt et al. (2000) implemented in-service teacher training programs that showed promising results. After the training, teachers expressed confidence in their ability to meet the needs of children with cancer. Typically, teacher training incorporated workshops that included lectures, video presentations, discussions, and a tour of the hospital (Brown et al., 2011). These workshops provided knowledge for the participants about pediatric 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).

**Laws and Services**

Current federal laws, like the Individuals with Disabilities Education Improvement Act (IDEIA 2004) and Section 504 of the Rehabilitation Act of 1973, do not fully address the complex and varied needs of children with cancer. Despite IDEIA's intent to provide reasonable accommodations for students with disabilities in the least restrictive environment, children with cancer do not clearly fit into the law's existing category of "other health impairment" (OHI). The OHI category is too broad and does not adequately address the needs of children who are chronically ill and face complex medical needs that impact their ability to function adequately at school (Irwin & Elam, 2011). Additionally, since many children with chronic conditions do not qualify for special education services; it is imperative that general education and special education teachers receive training to meet the needs of this population (Irwin et al., 2018; Thies, 1999).

Due to misunderstanding of and gaps 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 a chronic illness, such as cancer (Hopkins & Hughes, 2015; Irwin & Elam, 2011; Thies, 1999; Zirkel et al., 2012). It is essential to maintain effective, ongoing communication between parents, medical, and school personnel (Brown et al., 2011; Thompson et al., 2015; Hopkins & Hughes, 2015). Thus, school and medical professionals must effectively collaborate to meet the needs of children with chronic illnesses. Additionally, with the increased complexity of various forms of chronic illness in children, the need exists for the development of coordinated and flexible care models that will guide medical and school providers when meeting the complex needs of children and their families (Irwin & Elam, 2011). Unfortunately, the literature reflects that sustained and effective collaboration between medical and school personnel have been inconsistent. Children and families often fall through the cracks educationally when absent for extended periods of time due to illness (Lum et al., 2017). Uncertainty regarding current laws, services, and providers further hinders a smooth continuation of educational services (Eaton, 2012).

**Successful Strategies: Collaboration & Effective Communication**

To effectively collaborate, hospital-based school liaisons and school-based liaisons are strongly recommended to effectively address the coordination of services (Lum et al., 2017; Shaw et al., 2011)**.** In a survey of parents of pediatric cancer survivors who received hospital-based liaison services, Northman et al. (2015) found that parents believed that liaison services had a significant and positive impact for their children. The parents reported that their children were more likely to have a formalized IEP or 504 plan. As a result of liaison services, parents reported improvements in their children's academic performance, home-school communication, and understanding of their child's unique cognitive and learning needs. Similarly, Northman et al. (2018) found that through liaison services, parents perceived that their children were progressing academically, understood their children's learning needs, and were better able to access school services. In 2016, Rubens et al. examined parent-reported outcomes of liaison services to assist families in obtaining services and advocating for their children. Families who received liaison services for multiple years reported that they were more successful in obtaining services and felt more confident in their ability to advocate for their children. The research suggests that liaison services should continue beyond school-reentry to assist parents, educators, and school personnel to address long-term academic needs (Centers for Disease Control and Prevention [CDC], 2017; Northman, et al., 2018; Trask & Peterson, 2016).

Ongoing communication should occur between school and medical personnel to meet the needs of a student with cancer. To ensure communication is maintained, liaisons should be established at both the school and the hospital. At the school level, a school psychologist (Lum et al., 2017; Selekman, 2017; Root et al., 2016; Harris, 2009; Nabors et al., 2008, Nabors & Lehmkuhl, 2004) or school counselor (Kaffenberger, 2006) should serve as the liaison. To address academic needs of children experiencing late effects from treatment, the hospital-based school liaison would provide psychoeducation, advocacy, and consultation services to the families, the educators, and medical staff (Northman et al., 2015). A multidisciplinary team (MDT) or a Section 504 team consisting of the school psychologist, serving as the coordinator of care (Root et al., 2016; Harris, 2009), a hospital-based school liaison (Northman et al., 2015), school administrators, school nurse, teachers, school personnel, the child with cancer (if appropriate), and parents and family members convene to develop plans for continued education during and after treatment.

For children whose educational performance is significantly impacted and who will need special education services, an Individualized Education Program (IEP) should be developed (Brown et al., 2011; Hay et al., 2015; Prevatt et al., 2000; Northam et al., 2018). If the child's medical condition does not adversely affect the child's academic performance, 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; Moore et al., 2009). Additionally, DaPaepe et al. (2002) and Pufpaff et al. (2015) encourage that the school nurse should develop an Individualized Health Plan (IHP), which provides training about the child's medical condition, 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.

Ultimately, the MDT or a 504 team should develop and monitor flexible educational and health care plans for the child (Bessell, 2001; Clay et al., 2004) and determine how the student will be instructed: home schooled, homebound instruction, or by a certified hospital teacher (Friend & Bursuck, 2019). Multidisciplinary teams should consider a range of school and classroom strategies to utilize 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, 2019; Hay et al., 2015; Shaw & McCabe, 2008). The school-based liaison and hospital-based school liaison will be responsible for keeping the teacher and MDT or 504 members apprised of any changes in the child's educational and health progress and if school functioning changes occur, late effects arise, and whether behavioral or psychosocial issues emerge (Northman et al., 2018; Root et al., 2016; Harris, 2009). Table 1 provides a suggested list of roles, responsibilities of, and services provided by multidisciplinary team members.

***Table 1.*** Potential roles and responsibilities for multidisciplinary team members

| Multidisciplinary Team Members | Roles and Responsibilities |
|---|---|
| The Child with Cancer (if developmentally appropriate) | 1. Share information about their illness with classmates or other peers.<br>2. Describe their interests in social, athletic, and extracurricular activities.<br>3. Discuss concerns, such as hair loss, body image, academic concerns, and fear of recurrence, etc. (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 (National Asthma Education and Prevention Program [NAEPP], 2003).<br>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).<br>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).<br>4. Educate their child to develop age-appropriate self-care skills (NAEPP, 2003). |
| General Education Teachers | 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).<br>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, 2019).<br>3. Maintain classroom social connections by establishing ongoing peer communication and collaboration through technology and letter writing (Beeman & Henderson, 2012; Bessell, 2001; Shaw & McCabe, 2008). |
| Special Education Teachers | 1. Collaborate with general education teachers to develop specialized instruction, including classroom academic, environmental, and social/emotional accommodations and modifications (Friend & Bursuck, 2019; L'Hotta et al., 2023). |

| Multidisciplinary Team Members | Roles and Responsibilities |
|---|---|
| School Administrators | 1. Oversee that an action plan is properly implemented, and necessary materials are provided (Thies, 1999).<br>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, 2019).<br>3. Promote normalcy and the full integration of the child into school (Spinetta et al., 2009). |
| 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).<br>2. Help school personnel, teachers, and classmates understand their roles in supporting the child, family, and siblings (Harris, 2009; Kaffenberger, 2006).<br>3. Discuss school re-entry expectations (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 could request, with parent permission, the records for the team to review (Katz & Madan-Swain, 2006).<br>2. Serve as a liaison between the hospital and school to analyze a child's current level of functioning within an eco-triadic model of home, hospital, and school settings (Harris, 2009).<br>3. Oversee implementation, ongoing review, and evaluation of the child's IEP and health plans (Harris, 2009).<br>4. Conduct psychological testing of children who have brain tumors and may need social and academic support, inform general education teachers and parents of potential for cognitive sequelae, and provide input into the IEP (L'Hotta et al., 2023). |
| School Guidance Counselor | 1. Provide resources and coordinate support services for the child and the child's family (Kaffenberger, 2006).<br>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 et al., 2010).<br>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). |

| Multidisciplinary Team Members | Roles and Responsibilities |
|---|---|
| School Health Liaison (School Nurse) | 1. Provide direct services and medication management for students with chronic illness (Centers for Disease Control and Prevention [CDC], 2017).<br>2. Serve as the coordinator of care by providing healthcare assessment, intervention, and follow-up for all children within the school setting. Develop and implement individualized health plans (IHP) and emergency care plans (CDC, 2017).<br>3. Advocate for children and families to assist them in receiving needed services and medical care for their child (CDC, 2017).<br>4. Spearhead school-wide efforts (e.g., assessing health status and addressing barriers, working with parents and families to facilitate access to medical services, conduct parent and caregiver classes on health topics; foster a safe-school environment with school staff) to reduce chronic absenteeism of students with chronic health conditions (CDC, 2017). |
| Hospital-Based School Liaison: | 1. Help parents and school personnel address the child's needs during treatment, upon school-reentry, and long-term as academic, medical, and social needs evolve (Northman, et al., 2018; Trask & Peterson, 2016).<br>2. Maintain ongoing communication with school-based liaisons to address the current and long-term needs of a child with cancer (Lum et al., 2017; Shaw et al., 2011). |
| Hospital Health Care Social Worker: | 1. Arrange for at-home services when needed. Help school counselors with the transition from the hospital back to the school (Claiborne & Vandenburgh, 2001). |
| Hospital Oncologist and Oncology Nurse: | 1. Describe possible illness-related complications that may impact educational performance (Prevatt et al., 2000). |
| Hospital Child Life Specialist or Psychologist: | 1. Can assist if the child is displaying any behavioral problems, noncompliance with treatment, or emotional symptoms such as stress, anxiety, or depression (Prevatt et al., 2000). |
| Speech-Language Pathologist (SLPs) | 1. Often provide services for children who have CNS tumors (L'Hotta et al., 2023). |
| Occupational Therapist (OT) | 1. Often provide services for children with leukemia, bone cancer, CNS tumors (L'Hotta et al., 2023). |
| Physical Therapist (PT) | 1. Often provide services for children with leukemia, bone cancer, CNS tumors (L'Hotta et al., 2023) |

**Successful Strategies: School Reentry**

After cancer treatment, many children face long-term effects that impact school functioning and academic performance for many years to come. Common treatments, like chemotherapy and radiation, have not evolved much over the years and can have significant side effects upon growing children (Children's Cancer Research Fund, 2017, 2022; Gartin & Murdick, 2009; L'Hotta et al., 2023). School psychologists, school nurses, and school-hospital liaisons can examine the interplay between the home, the hospital, and school settings for the child in order to facilitate the child's successful transition back into the school setting (Northman et al., 2018; Harris, 2009). In addition to educational recommendations, the school-hospital liaison can be instrumental in visiting the classroom to educate the peers about their classmate's illness and treatment and provide ongoing consultation to the school and parents to facilitate immediate and long-term accommodations (Northman et al., 2018).

Upon school reentry, it's important that the school-based and hospital-based liaisons ensure health care and related services are well-coordinated with families, school personnel, and medical specialists (Wikel & Markelz, 2023; Young et al., 2021; Northam et al., 2018; Root et al., 2016; Shaw et al., 2011; Moore, 2009). The key to the success of a re-entry plan is for team members to develop comprehensive, individualized programs that provide academic and social support for the child and their family (Young et al., 2021; Wikel & Markelz, 2023). 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; Eaton, 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 (Wikel & Markelz, 2023; Friend & Bursuck, 2019; Sewell, 2012). If the family and child feel comfortable and sense that their input is welcomed, the devised plan will likely produce successful outcomes, including improved school attendance and feeling well-connected to peers (Wikel & Markelz, 2023).

Young et al. (2021) found that many childhood cancer survivors expressed anxiety, sadness, and depression leading to feelings of inadequacy in comparison to their peers. Many parents reported that their children had been bullied at school leading to devastating effects on their child's social and emotional well-being. On the other hand, some children and families indicated that their child received positive support and encouragement from classmates, friends, and siblings. Ultimately, children and adolescents expressed that having a strong friendship was the most significant factor impacting their ability to navigate school. Embedding evidence-based school-wide social-emotional learning (SEL) approaches can promote empathy, enhance and maintain positive relationships, and help prevent bullying of childhood cancer survivors as well as promote positive relationships amongst all students. Oftentimes, general education teachers can seamlessly integrate SEL practices during classroom routines, rituals, and learning activities without singling out the child with cancer. At times, targeted intervention programs (Young, et al., 2021) and peer workshops should be conducted with classroom peers (Root et al., 2016; Brown et al., 2011; Sentenac et al., 2012). Peer workshops provide a forum for healthy classmates to have their questions and misconceptions about pediatric cancer answered in order to reduce their worries and distress about childhood cancer. The program helps to foster interaction between the child with cancer and his or her peers. Peer education efforts, including

class discussions prior to school reentry and letters home to the parents of healthy classmates, help foster a sense of compassion for the classmate with cancer and should help eliminate the potential for bullying (Root et al., 2016; Sentenac et al., 2012). Table 2 provides a list of common late effects from cancer treatment and suggested referrals.

***Table 2***. Common late effects of pediatric cancer treatment and suggested referrals

| Some Common Late Effects | Possible Referrals |
|---|---|
| Neurocognition | Refer for psychological evaluation and screen for cognitive impairments and evaluate school, living, and work-related needs (L'Hotta et al., 2023). |
| Hearing Loss | Refer for audiology (Children's Oncology Group, 2023) and SLP services (L'Hotta et al., 2023). |
| Speech and Language | Refer for SLP services (L'Hotta et al., 2023). |
| Physical Changes | Refer for PT services to assist with physical management, gait, and use of prosthetic devices (for students with amputations) (L'Hotta et al., 2023).<br>Refer for OT services to assist with daily living and life skills (L'Hotta et al., 2023). |
| Fatigue | Referral for PT, psychological, or other related service providers for services. (L'Hotta et al., 2023). |
| Psychosocial | Referral for psychological services to emotional adjustment issues and to a pain rehabilitation clinic for ongoing pain (L'Hotta et al., 2023). |

## Recommendations

Clear educational policies and procedures need to exist to ensure the continued education and inclusion of a child with chronic illness, like pediatric cancer. The child and family should be at the forefront of the plan (Case-Smith, 2004). It is critical for schools to establish a multidisciplinary team with clearly defined roles and responsibilities. To effectively educate a child with cancer, close collaboration of team members, including hospital-based and school-based liaisons, is essential for long-term support of students with neurocognitive and other late effects from cancer treatment (Brown et al., 2011; Harris, 2009; Moore, 2009; Northman et al., 2018; Northman et al., 2015; Barrera et al., 2005; Gartin & Murdick, 2009). Finally, research strongly indicates that pre-service educators, general education teachers, special education teachers, and school personnel need relevant medical, educational, and social-emotional training and support to provide appropriate academic accommodations, social inclusion, and essential medical care (Young et al., 2021; Wikel & Markelz, 2023; Root et al., 2016; Brown et al., 2011, Nabors et al., 2008; Irwin et al., 2018; Selekman, 2017; Irwin & Elam, 2011).

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