



Beyond Cancer: Educational considerations during and after treatment for the child with cancer and their families.

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INTRODUCTION

Cancer affects individuals across all age groups, ranging from infants to adults. Although a rare phenomenon, approximately 15,000 children aged 0 and 20 are diagnosed with some form of cancer each year in the United States. Byran et al. (2021) emphasize that a child's cancer diagnosis and its ensuing treatment can have both immediate and life-long ramifications on the child's cognitive and emotional development. While advancements in medical technology have led to significantly improved outcomes in childhood cancer over the last 20 years, it remains the second leading cause of death among children (Losinski & Ennis, 2018). The most common types of cancers affecting children and adolescents include leukemias, brain tumors, central nervous system cancers, and lymphomas (CDC, 2023; NCI, 2021). Treatment plans are diverse, often mirroring the complexity seen in adult cancer cases. For instance, the treatment for Acute Lymphoblastic Leukemia generally spans 24 to 36 months and includes multiple phases: induction, consolidation, and maintenance (NCI, 2021).

IMPACTS TO LEARNING

The Children's Oncology Group (2008) observes that a child's age at diagnosis, the specific type of cancer, and the nature of its treatment are key factors that determine both immediate and long-term educational impacts. Adolescents being treated for cancer may struggle in one or more of the following areas (NCCS):

- Difficulty in learning and understanding new information
- Difficulty and limitations in executing mathematical operations like multiplication and division
- Struggling to engage in conversations and/or recognize social cues
- Challenges in maintaining sustained focus and attention Issues with organizing data in a sequential manner Difficulty in understanding the essence of written material, even when reading the words is not a problem
- Delays and difficulty in accomplishing tasks within prescribed time limits
- Challenges in adapting to newly introduced educational material
- Difficulty in retaining visual stimuli as opposed to auditory information
- Challenges and difficulties in formulating plans and organizing tasks efficiently

It's important to emphasize that each child, or adolescent who is treated for childhood cancer will have a unique experience, and each solution will need to be carried out in an individualized manner. Children may experience, all or none of the problems discussed; problems with memory, or math computation may not emerge until much later after the child has been off-treatment in survivorship status (Losinski & Ennis, 2018, Richard et al., 2108).



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Educator Awareness

Owing to the rarity of childhood cancer and the array of types, treatment modalities, and varying levels of awareness and resources available to educational teams, educators often grapple with how best to support these students and their families during and after treatment (Brown, 2006; Losinski & Ennis, 2018; Marchak et al., 2021).

A recent study demonstrated only 25% of educators surveyed had experience working with a child or adolescent with cancer (Oth & Schienemann, 2022).

Collaboration & Planning

In the United States, children diagnosed with cancer are most frequently referred to specialized regional cancer centers. These centers use a biopsychosocial developmental model to guide the comprehensive treatment of both acute and chronic conditions (National Cancer Institute, 2023). This model, initially introduced by Engel in the 1980s, holistically assesses a multitude of interconnected factors that influence a child's well-being throughout the treatment journey (Engel, 1980; National Cancer Institute, 2023). Interdisciplinary teams, comprising pediatric oncologists, nurses, physical and occupational therapists, social workers, counselors, educational coordinators, and other allied health professionals, work collaboratively to optimize patient outcomes. These team members are essential contributors to understanding the child's needs during and after treatment. However, it is unrealistic to assume all team members may be able to meet at the same time, therefore Hays et al. (2015) suggest appointing a single point of contact such as the school psychologist, to work with the hospital educational liaison, a nurse practitioner, or hospital social worker in order to obtain communication, and documentation from the hospital (based upon parental preference and after appropriate consents have been obtained).

This information often forms the basis for evaluations mandated by state and federal laws (IDEA, 2004). Some educational teams may find that a Section 504 plan suffices for accommodating the child's needs. However, frequently with childhood cancer, an Individualized Education Plan (IEP) may be necessary, particularly if specialized services are required. This decision point is crucial as it directly impacts the scope of services provided and the school's legal obligations (Hays et. al, 2015; IDEA, 2004).



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LRE - SCHOOL RE-ENTRY PLANS

The intensity, and concerns during inductive treatment often make it difficult for students to come to school during the initial treatment phase. Plans for student re-entry to school should begin at the time of the child's diagnosis, school re-entry programs can ease the transition back to the classroom for children with cancer (Canter & Roberts, 2012; Thompson et al., 2015).

A meta-analysis by Thompson et al. (2015) found that providers should be expected to provide at a minimum information about the child's disease process, and the manner in which it is likely to impact the educational process. Additional information familiarizing teachers and peers with the child's disease process can also be identified and shared based on the wishes of the child with cancer and their family.

Considerations for infection control within the classroom, such as instruction in handwashing, and cleansing of the classroom areas can also help put parents at ease, and disclosure of increased community spread for certain types of illness such as influenza, and other communicable diseases can also be helpful.

Determining the Optimal Educational Setting "Least Restrictive Environment"

In determining the "Least Restrictive Environment" (LRE) for a child with cancer, several factors need to be considered. The team must examine the child's unique academic, social, and emotional needs, while also weighing in on the medical limitations and precautions needed. The LRE principle under IDEA serves as a foundational guideline for educational teams in planning and implementing educational services for children with disabilities. The main idea is to include children with disabilities in general education classrooms and settings whenever possible, provided their needs can be met in those settings. Special education services should be considered a supportive mechanism to facilitate this inclusion, rather than as a separate placement (IDEA, 2004).

Travel distance to treatment centers for each family varies, however, the burden of getting children to specialized care can be immense. Fluechel et al. (2014) revealed that children and adolescents being treated for cancer from rural regions traveled more frequently, had higher out-of-pocket travel, missed more school, and were more likely to repeat a grade. Many schools implement technology or move students to remote learning as a solution for managing such intense travel plans.

While modern technology makes remote learning possible, research suggests that there are several advantages to a thoughtfully planned return to traditional classroom settings. Kim & Yoo (2023) found that students who spent time with peers on a regular basis and had an opportunity to form and maintain friendships experienced increases in overall resilience during treatment, than those who did not. Similarly, the school and staff themselves can act as additional support for the overall resilience of parents, and siblings who may also be struggling with support systems and looking for resources to help them to cope (Losinski & Ennis, 2018; Hopkins, 2016; Hay et al., 2015).

Further new evidence suggests that remote learning for specialized populations can have broader impacts on learning which makes it even more important for educational teams to carefully weigh the benefits of remote work for the student, with in-person learning (Carey et al., 2022).



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LRE - School Re-Entry Plans

A recent study conducted post-COVID-19 examined the experiences of childhood cancer survivors engaged in remote learning. The study found that attention dysregulation, commonly seen in pediatric cancer patients and survivors, particularly those who are undergoing or have undergone CNS-delivered chemotherapy (chemo placed directly into the spine), made remote instruction particularly difficult. In addition, parents reported that the diminished availability of the support systems normally present in classrooms — such as immediate feedback from educators—adversely impacted their child's academic overall success (Carey et al., 2022). While many peers were able to keep pace, those with accommodation needs fell further and further behind, with no real route to recovery, adding this to the weight placed on the primary caregivers' responsibility to coordinate and maintain a school routine, on top of the demands of cancer treatment, becoming an unnecessary burden with increased feelings of concern and guilt (Carey et al., 2022). Hence, as previously noted, having multiple contingency plans for a child who is on treatment, may offer broader solutions for some teams.

It is important to note that the "Least Restrictive Environment" will vary from child to child, depending on their specific needs and the supports that are necessary for them to receive a Free Appropriate Public Education (FAPE), another core concept in IDEA. Remaining flexible, with and ensuring teams have a variety of contingency plans in place which allow them to pivot based on the child's health status are key factors in supporting children and family as the focus on regaining homeostasis have a cancer diagnosis (Hay et al., 2015; Losinski & Ennis, 2018)

Accommodations:

According to St.Jude's (2022) accommodations for a child with cancer may include the following:

- Preferred seating which provides closer access to a restroom, teacher, technology, or teacher
- A locker, or two lockers located close to their classrooms
- Electronic Textbooks, or a second copy of texts
- A classmate, or scribe to take notes, or allowance of recording device
- Educational technology that allows for distance learning (laptop, or IPAD)
- Video linked classroom
- Weekly study guides, or teachers' notes
- Extended time on test and assignment
- Shortened or modified assignments, or use of verbal competency
- Use of elevator
- Verbal, or email prompting of assignments
- Permission to leave class early to walk in uncrowded hallways
- Buddy system for visits to the school nurse's office
- Permission to wear a hat at school
- Prompt phone contact with parents when another student in the classroom has a contagious illness
- Rest break in the classroom, or at school nurse's office



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