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# Academic Continuity and School Reentry Support as a Standard of Care in Pediatric Oncology

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## Abstract

Clinicians agree that return to school after diagnosis promotes the positive adjustment of children and adolescents with cancer; however, the school reentry process can present challenges. The aim of this review was to critically evaluate the literature on school reentry support for youth with cancer. Seventeen publications were identified. School reentry services were well-received by families and educators; increased teacher and peer knowledge about childhood cancer; influenced peer and educator attitudes toward the patient; and improved communication and collaboration between patients/families, school, and the healthcare team. Evidence supports a strong recommendation for school reentry support for youth with cancer.

### Keywords

childhood cancer; psychosocial; school reentry

## INTRODUCTION

Children and adolescents diagnosed with cancer are frequently absent from school because of treatment and treatment-related side effects.[1,2] Absences can be a problem both during and after treatment but are most pronounced in the year after diagnosis.[1] Although empirical support is limited, clinicians agree that a return to the student's community school

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can facilitate a sense of normalcy, improve health-related quality-of life, and promote positive adjustment, academic progress, and socialization of the child or adolescent with cancer.[3,4]

"School reentry" refers to the process of returning to school after diagnosis and/or treatment for cancer[5] and can present challenges for the healthcare team, patients, classmates, parents, and teachers. Healthcare teams report being unsure how to help parents navigate the school system.[5] Patients may worry about their physical appearance or fear that they would not be able to keep up with activities, while peers may have concerns about catching the disease.[1,3,6] Some parents report concerns about safety and teasing; they are unclear about their role in school reentry[1,3,6] and feel that their children are not receiving all the school services needed.[5] Upon reentry, some parents report that schools are unsupportive toward their child's special needs or, alternatively, are overly accommodating of the student.[7,8] Despite these concerns, data from teachers and peers suggests that the majority of children return to school and fit in well with their peers.[9]

Given the rarity of childhood cancer, it is not surprising that educators report having little or no training or experience in working with children with cancer.[5,10] As a result, teachers worry about their lack of knowledge about cancer and how other children in the classroom will adjust.[1,3,6] They may feel unprepared to support the educational needs of students with a chronic condition such as cancer.[11,12] Educators desire training and have reported that if they received specific guidance on how to help patients returning to school, they would be more consistent, patient, understanding, and involved in providing support to these students.[7,13]

The Association of Pediatric Hematology Oncology Educational Specialists (APHOES) and the International Society of Paediatric Oncology (SIOP) recommend that school support for students with cancer begin at diagnosis, that school reentry programs be offered, and that clear communication between school and hospital personnel be ongoing.[14,15] Despite these recommendations, an evidence-based standard of care has not yet been established. There are a wide range of school support programs and approaches (e.g., reentry programs, hospital-based schools, homebound instruction, use of videoconferencing technologies) that are designed to mitigate the impact of childhood cancer on the school experience. As most have not been studied systematically in pediatric cancer, this review focuses specifically on school reentry support for school-age youth (ages 4–18) who are returning to a community school after initial diagnosis and treatment for a malignancy. Recommendations for school reentry described here are predicated on the assumption that children with cancer will return to school in the community as soon as they are medically able, although there is considerable variability between individual providers (i.e., pediatric oncologists) and across oncology programs regarding what constitutes a "timely" return to school.[16] In addition, return to school is dependent upon family comfort, which is also quite variable.

## METHODS

To develop this standard, we used methods described by Wiener et al.[17] in this special issue for the Standards for Psychosocial Care of Children with Cancer and Their Families project. Our search employed four databases: PubMed, PsychInfo, CINAHL, and ERIC. Search criteria included English-language, peer-reviewed literature published from March 1, 1995 to March 1, 2015, with participants ages of 4–18 and a history of any malignancy. Exclusion criteria eliminated literature that was not empirical research (with the exception of consensus statements from expert panels) and literature about non-cancer diagnoses, patients over age 18, and foreign language publications. Articles were retained that included children with cancer as one disease group among other illnesses. Specific search terms included “school reentry,” “school reintegration,” “school intervention,” “school liaison,” OR“schools”ANDcancer-related terms AND “child” OR “adolescent” OR “pediatric” OR “paediatric” OR “youth” OR “children” (using indexed MeSH terms). Searches were supplemented with a manual review of the reference lists of included studies and ultimately resulted in a total of 529 citations. Authors followed PRISMA guidelines, leaving 17 articles for inclusion in the synthesis of evidence (Figure 1 in Supplemental Materials).

The study team was comprised of representatives from the fields of psychiatry, psychology, nursing, and education. External reviews were conducted by members of APHOES and the Council for Exceptional Children’s Division of Physical, Health, and Multiple Disabilities, an attorney at an Education Law Center, a school administrator, and parents and survivors of childhood cancer.

## RESULTS

The search strategy identified 17 peer-reviewed papers, including two meta-analyses and one systematic review of the literature. This literature is summarized in Table I in Supplemental materials. Previous seminal work on school reentry that preceded the selected search timeframe was captured and synthesized in the meta-analyses included in this review.[18,19] Studies indicated that school reentry efforts, in their various formats, were well-received, well-accepted, and deemed helpful by parents and educators.[10,20,21] In general, school reentry programs and approaches varied widely across studies but commonly targeted parents, school personnel, or the patient’s classmates, rather than the patients themselves. Programs typically included written, electronic, or in-person communication about diagnosis and treatment, its impact on the school experience, and suggested services of accommodations. For more detailed description of school reentry services in the reviewed studies, please refer to Supplemental Materials, Table II.

Across nine publications, including two meta-analyses,[18,19] one systematic review,[1] two individual quantitative studies,[10,22] and four qualitative studies,[6,23–25] findings consistently indicated that school reentry programs increased educators’ knowledge about the medical and psychosocial aspects of cancer, led to more positive teacher attitudes toward the child with cancer, and increased teachers’ confidence and comfort levels managing issues encountered by patients with cancer who are returning to school. Of note, one study[6] reported that increased knowledge about pediatric cancer might inadvertently increase worry and concern by teachers regarding side effects and academic achievement (although it should be noted that increased levels of worry, when appropriately directed, might result in more effective school support for the child with cancer).Additionally, two studies found that educators’ increased knowledge about diagnosis and treatment improved their ability to provide more comprehensive educational programming suited to students' specific needs.[23,25]

Similarly, four studies, including two meta-analyses,[18,19] a systematic review,[1] and an individual qualitative study,[24] indicated that school reentry programs increased peers' knowledge concerning the medical and psychosocial aspects of cancer and improved peers' attitudes toward and increased interest in interacting with the student with cancer. In a meta-analysis of six intervention studies, increased knowledge among classmates was found to be associated with less fear of and a more positive attitude toward the child with cancer.[18]

Evidence for the impact of school reentry support on the patient is limited, and findings are less consistent than research assessing the impact on school personnel and peers. Helms et al.[18] reported that school reentry support both enhanced the academic achievement of and lowered levels of depression in students with cancer. In small qualitative studies, parents reported decreased peer teasing[6] and improvement in their child's social adjustment and learning.[23] Additionally, a quality improvement study of a school liaison program for pediatric cancer survivors reported that those in the program were more likely to be receiving special education services,[20] which may indicate increased access to noteworthy school supports. In a feasibility study of a 4-month reentry intervention, parent-report on the Behavioral Assessment System for Children (BASC-2) were normal at pre- and post-testing, but quality-of-life (QoL) decreased over the course of the study;[26] this finding, however, may be due to expected decrements in QoL over the first months of treatment.

Evidence about the impact of school reentry support on parents was also very limited. Three separate qualitative studies reported that school reentry support may strengthen parents' advocacy skills for their child in the school setting[23] and decrease parent concerns related to peer teasing[6] but have no impact on parent concerns regarding their child's safety.[6] Communication and close collaboration among medical staff, school personnel, and families was identified as a critical component of providing effective services to students.[5,7,21,27,28] Stakeholders reported that educators need to keep in touch with children as they recover, that parents and teachers must work together to facilitate a smooth transition back to school, and that support from teachers, tutors, and the hospital staff was instrumental in creating a positive school re-entry experience. [27,28] To support collaboration and address communication challenges, several reviewed studies suggest a designated team member (e.g., NP, school liaison) may be helpful.[5,15,20,23]

## DISCUSSION

Our review suggests that school reentry support should be provided to youth diagnosed with cancer by a well-trained, experienced pediatric oncology team member who will coordinate communication between the child/family, school, and health care team and should, at a minimum, focus on providing information to school personnel about the impact of disease and treatment on the school experience. Support may include verbal/written communication with the school, an individualized academic plan, guidance for parents around resources and processes, a school visit to educate peers and school personnel, educator workshops, or formal school liaisons. Two studies documented a positive impact of comprehensive school liaison programs,[20,23] and while these results are promising, further study must be conducted before recommendations can be made about this specific model of support. If resources are available, the use of a hospital-school liaison with expertise in both education and medical systems may help to bridge the gap in communication and increase coordination of efforts across systems and stakeholders.[29]

Methodological and conceptual weaknesses of the current evidence base limit the ability to draw strong conclusions about the impact or effectiveness of school reentry support. In general, studies were rated as low to very low quality evidence because of small sample sizes, lack of control groups, and the lack of randomized clinical trials or between-site comparison trials. Outcomes measures were psychometrically limited and focused on peer knowledge or satisfaction of teachers and/or parents, with little work examining metrics such as numbers of children on 504 plans or Individualized Education Programs (IEPs). Neither study methods nor reentry approaches were informed by a clear theoretical basis or model; as a result, goals and outcomes of school reentry have been unclear to date. There were no standardized approaches to school reentry support (Supplemental Materials, Table II). Programs varied by content, who conducted the program, and to whom the interventions were directed. Finally, there is lack of evidence for improved social or academic outcomes when children receive school reentry services.

Although decisions regarding return to school are dependent on pediatric oncologists and the comfort of caregivers, there is agreement among parents, health care team members, and professional/advocacy organizations (e.g., APHOES, SIOP) that children with cancer can benefit from strategic support to facilitate school reentry.[15,30] Additional research, however, is needed to direct best practice. Future research should address optimal timing and necessary components of support; impact of school reentry support on social or academic outcomes for children with cancer; potential negative effects or unintended consequences on patients and peers; and best practices for providing ongoing educational assessment and support for students with cancer beyond the return to school after diagnosis.

Current research focuses primarily on younger school-age children; research on best practices for students in middle and high-school, when there are unique academic challenges and complexities (e.g., more classes, teachers, and independence), was very limited. Evaluating which components of support are most beneficial to patients will aid in determining allocation of limited financial and personnel resources at childhood cancer centers across the country. Specific focus should be given to patients with brain tumors, who are at risk for significant academic,[31] and social difficulties[32,33] and therefore may require more intensive support in school and interventions that are different in scope, timing, and content than those that may be beneficial for patients with other diagnoses. Research noting social isolation, victimization, and low social acceptance of children surviving brain tumors[32,33] highlights the need for school reentry or liaison programs to mitigate poor outcomes for this vulnerable population.

The most significant organizational barrier to implementation of this standard is cost of programming and personnel. Institutional resources often limit availability of personnel dedicated to school support, as programming is non-revenue generating and thus may be perceived as cost-prohibitive.[34] Another barrier to implementation is large patient volumes and/or centers with large catchment areas that span multiple states and many school districts[3] which may present logistical challenges at the organizational level. Developing procedures and materials to educate school personnel from a distance (i.e., through written, telephone, or electronic communication) may prove helpful in addressing these barriers, but current research in this area is non-existent.

Overall, the current evidence regarding the value of school reentry programs is of low quality based on our assessment of the scientific rigor of the reviewed studies. Findings across studies, however, consistently demonstrated positive endorsement of school reentry programs by parent and education stakeholders and improvements in teacher and classmate understanding of the illness and opinions about the child with cancer. Given these consistently reported benefits of school reentry support, the minimal risk this support poses to the child with cancer, their family, their classmates and school personnel, and the potential harm to the patient in not providing this support, we strongly recommend that children with cancer be provided with school reentry support after diagnosis by a member of the childhood cancer care team (Supplemental Table I). Currently, there is a notable lack of evidence to endorse the essential elements of school reentry support, including the optimal type and timing of interventions and the necessary expertise or qualifications of personnel implementing the interventions and coordinating support.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

## Acknowledgments

Conflict of interest: Author MKI is the current Present of APHOES and author ME is Committee Chair of the APHOES Legislative Committee. ME is also the Vice President of the Division of Physical, Health, and Multiple Disabilities within the Council for Exceptional Children. While their participation in this standard development was critical (given their content expertise), lead authors ALT and RBN took care to reduce any possible bias by strict adherence to evidence based review, wording and GRADE assessment for each standard. MKI and ME participated in review of literature, developing standards and in preparing final manuscript; however, the entire writing team shaped and approved final working of each standard statement such that individual authors could not exert independent influence on how each was worded. Additionally, MKI and ME did not participate in the external reviews conducted by other members of their respective organizations. Communication about these reviews occurred between organization contact and authors RBN and ALT exclusively.

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## Abbreviations

| | |
|---|---|
| **BASC-2** | behavioral assessment system for children second edition |
| **QoL** | Quality-of-life |

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### Psychosocial Standard of Care

- In collaboration with parents, school-aged youth diagnosed with cancer should receive school reentry support that focuses on providing information to school personnel about the patient’s diagnosis, treatment, and implications for the school environment and provides recommendations to support the child’s school experience.
- Pediatric oncology programs should identify a team member with the requisite knowledge and skills who will coordinate communication between the patient/family, school, and the health care team.

## TABLE I

School Reentry Standard Summary of Evidence Table

| Standard | Evidence summary[1] | Methodology[2] | Quality of evidence[3] | Strength of recommendation[4] |
|---|---|---|---|---|
| a. In collaboration with parents, school-age youth diagnosed with cancer should receive school reentry support that focuses on providing information to school personnel about the patient's diagnosis, treatment, and implications for the school environment and provides recommendations to support the child's school experience<br>b. Pediatric oncology programs should identify a team member with the requisite knowledge and skills who will coordinate communication between the patient/family, school, and the health care team | School reentry programs and services were well-liked and appreciated by patients, families, and educators; increased teacher and peer knowledge about childhood cancer; influenced peer and educator attitudes toward the patient returning to the classroom; and required significant communication and collaboration between patients/families, school, and the health care team<br>Existing studies had methodological and conceptual weaknesses, including small sample sizes, lack of control groups, lack of randomized controlled trials, and lack of follow-up data regarding effectiveness and impact on patient's adjustment | Pre-post test designs, qualitative, quantitative, meta analyses, and a systematic literature review. No randomized controlled trials. Consistent findings evident | Low quality given consistent findings from lower level evidence studies | Strong recommendation given risk-benefit ratio (i.e., minimal risk to patients, families and educators and potential benefits of improving the child's teachers' and classmates' understanding of the illness and opinions about the child with cancer) |

[1] Based on summary of evidence table for that standard;

[2] Types of studies: e.g. RCT, cross-sectional, longitudinal; consensus; systematic review articles;

[3] Quality of evidence: High, moderate, low, and very low;

[4] Strength of recommendation: Strong or weak (based on GRADE quality criteria).