

ONCOLOGIST'S PERSPECTIVES AND FACTORS INFLUENCING SCHOOL RE-
ENTRY RECOMMENDATIONS FOR CHILDREN WITH ACUTE
LYMPHOBLASTIC LEUKEMIA

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June 25th 2012

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ABSTRACT

Currently, there are no established guidelines among pediatric oncologists regarding school attendance recommendations during cancer treatment. Practices vary widely, ranging from continued school attendance following the initial phase of cancer treatment to complete abstention from school for the majority of the treatment protocol. This survey project explored the current practices of attendance recommendations among oncologists as well as their knowledge and perceptions of how school absence affects their patients' academic and psychosocial functioning. In an attempt to better understand why oncologists make the school re-entry recommendations, a prediction model was created and found to significantly predict oncologist's re-entry recommendations.

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LYMPHOBLASTIC LEUKEMIA

A Thesis

Presented To the Faculty of the Department of Psychology
East Carolina University

In Partial Fulfillment of the Requirements for the Degree Masters of Arts in School Psychology

By

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CHAPTER 1: INTRODUCTION

During the past 50 years, pediatric cancer, leukemia in particular, has been re-classified from a terminal disease to a chronic illness. The National Cancer Institute's (2007) most recent report on cancer prevalence states that, although one out of every 300 school-aged children has cancer, 80% of those children will have a five-year event-free survival rate, suggesting a low probability of cancer reoccurrence. With this promising likelihood of survival, oncologists' focus of treatment must now include psychosocial adjustment and mental health care, as well as traditional physical wellness secondary to the physically and emotionally taxing process of cancer treatment.

Cancer management is an arduous process with treatments lasting anywhere from three months to five years. The average standard treatment schedule is nine months, with an additional three-year maintenance phase of treatment. For the child, this frequently means a lengthy initial hospital stay followed by a longer period of outpatient treatments (see Table 1 for a typical treatment schedule). It is typical for a child to miss a great deal of school in the beginning stages of treatment; however, even after returning to school, weekly and bi-weekly outpatient follow-ups, somatic complaints, and infections may increase school absences. For these reasons, an oncologist may recommend that a child stay home from school and restrict other activities during a portion or the entirety of the treatment. In fact, some hospital policies mandate that a child be withheld from school until the maintenance phase, effectively precluding school attendance for an entire school year (M. Jefferson, personal communication, July 15, 2010). Conversely, other oncologists suggest returning to school as soon as the initial treatment phase (induction) is completed, presumably to allow the child to resume relatively normal family and community

functioning. These different protocols exist despite the fact that no clear data exist on what the ideal return time should be and what factors should influence the decision.

*Table 1. Typical Treatment Schedule and Phase Description**

Phase	Description	Typical Length
Induction	Very intense chemotherapy designed to bring disease into remission.	1 month
Delayed Intensification	Chemotherapy given three months after disease remission has been achieved via induction	3 – 4 months
Consolidation	Chemotherapy designed to reduce the number of disease cells left in the body	4 – 8 months
Maintenance	Less intense therapy given after other phases if remission is successful.	2 – 3 years

**Information from LeMaistre, Shaughnessy & Stein (2010)*

The alternatives to traditional brick-and-mortar schools are in-hospital schools, school-driven homebound instruction, parent-driven home schooling, and cyber schools (available in some states), but there is no research on the effectiveness of instruction in these environments or information regarding how they compare to the typical school environment, particularly as it relates to psychosocial development. Research does indicate that, although there is no “typical” cancer experience, children who are treated for cancer tend to have a myriad of academic and psychosocial deficits caused by the iatrogenic late effects and/or from extended school absences (e.g. Brown & Madan-Swain, 1993; Weitzman, Klein Walker & Gortmaker, 1986). These effects include a decline in grades, grade retention, and clinical levels of anxiety and depression. Thus, it is important to discern how often and why oncologists are instructing children to stay home from school during treatment.

Current Recommendations for Returning to Daily Activities

When a child is considered to be at high risk for infection, the oncologist will often recommend in-patient care until the child returns to an acceptable level of risk. However, for those who are considered to be at a low risk of infection, recommendations regarding school return differ based on oncologist preference (or hospital policy). Although most oncologists recommend that care should continue from home and the out-patient clinic, there is a great deal of variability on whether a child should be permitted to engage in regular activities, such as extracurricular activities, school, or even camps for children with cancer. The American Society for Hematology and Oncology does not report any written standard for this and many hospitals create their own local policies, which may include leaving the recommendations to each oncologist. For instance, a researcher in the United Kingdom reported that their hospital's policy advises children to return to school even when neutropenic (i.e., at an increased risk for infection secondary to low neutrophil count), with the caveat that teachers report any infections in the classroom to the parents of the patient (Hawkins, 2009). To the best of this researcher's knowledge, no documented recommendations have been made for children in the United States. It is known, however, that some children attend school and overnight camps after the initial induction phase of treatment, which suggests that risk of infection need not preclude participation in typical daily activities.

Although it is assumed that risk of infection is the primary reason to withhold children from school or daily activities during treatment (M. Jefferson, personal communication, July 15, 2010), there may be other reasons that impede participation in typical school settings including, but not limited to, chronic pain, fatigue and socioemotional issues such as depression and anxiety.

Oncologists' Reasons for Recommending Abstinence

Anecdotally, oncologists give several reasons for the recommendation to abstain from attending traditional schools (M. Jefferson, personal communication, July 15, 2010). Some examples are a decrease in school tolerance secondary to fatigue and pain; parental concern; and perhaps most salient, a potential increase in infection risk. The risk for infection is quite significant with certain types of cancer, such as leukemia, primarily due to the cancer itself or the iatrogenic effects of cancer therapies. Cancer treatments often affect the immune system via innate or adaptive immunity, which decreases the body's ability to fight infectious pathogens (Walsh et al., 2006). Infections and subsequent complications caused by infections are often the reason that children succumb to cancer. However, research indicates that the source of deadly infections, such as staphylococcus, is typically found in hospitals, not in schools (Auletta, O'Riordan & Nieder, 1999).

Other physical reasons why oncologists may consider withholding their patients from school are tolerance issues, such as fatigue and pain. Approximately 75-100 percent of patients report significant fatigue, making it the most commonly reported issue in cancer treatment (Meeske, Katz, Palmer, Burwinkle, & Varni, 2004). Though the reasons for fatigue are largely unknown, the effects of fatigue on cancer treatment are well-documented (Winningham, et al. 1994). Fatigue often leads to issues with medical adherence due to diminishing physical and psychosocial functioning.

Pain is also a major issue in cancer treatment with 26 percent of an outpatient Acute Lymphoblastic Leukemia (ALL) sample reporting pain (Miser, Dothage, Wesley, & Miser, 1987). Pain in cancer is often difficult to manage. Though many patients receive narcotics, they do not adequately control for pain and the side effects (e.g., nausea, sleep difficulties) are

unfavorable. Typical non-steroidal anti-inflammatory drugs (NSAID) are contraindicated due to the antipyretic effects that complicate infections by making febrile episodes less detectible (Miser et al., 1987). Both pain and fatigue can make school attendance difficult, and possibly interfere with treatment, making both logical reasons for withholding patients from school. Nonetheless, there appears to be no established guidelines or research supported strategies for oncologists to reference when making decisions about school attendance. By understanding the concerns of the oncologists, we can target additional research and/or interventions intended to help patients return school more quickly. A quicker return to school has been found to be optimal in the reduction of academic and/or psychosocial issues (discussed below). If children are not getting more infections from schools, it stands to reason that they should return to school as soon as they feel well enough (i.e., decreased fatigue and/or pain) so as to mitigate the negative effects of absences, and increase the positive effects of school attendance. If school intolerance due to fatigue and/or pain is the primary issue, then individualized graduated school reintegration programs can be developed.

It is unclear whether oncologists are aware of the academic and psychosocial issues that their patients face when school absences become excessive. Though disease-specific expertise has been reported to be a factor in mortality of cancer patients (Shanafelt et al., 2012), it is unknown whether an oncologist's understanding of psychosocial and academic sequelae factors into "experience" (i.e., years post fellowship). Whether oncologists who are aware of these issues base school reentry recommendations on this knowledge is also unknown. By understanding oncologists' knowledge and perceptions on this matter, we can create interventions for dissemination to oncologists and members of the treatment team that best support the needs of children with cancer.

School Absences in Children with Cancer

As stated, children with chronic illnesses, including cancer, have a higher rate of absences than their healthy peers (Cook, Shaller & Krischer, 1985). Although absences are understandable, there are potentially negative academic and socioemotional consequences associated with school absences, including higher school dropout rates (Weitzman, 1986). Absenteeism among children with cancer has been studied for over thirty years. Cook, Shaller and Krischer's (1985) seminal paper on absenteeism and chronic illness found that the mean number of days absent for children with cancer was 16.9 days ($SD = 26.6$); the national average for school absenteeism was 4.9 days. In fact, research indicates that children with cancer miss more school days when compared to children with other chronic illnesses, such as diabetes and sickle cell disease (Charlton et al., 1991). More specifically, Charlton and researchers report that children with cancer have a unique absence pattern of one long absence ($m = 91$ days) followed by regular shorter absences for follow-up or monitoring. Reasons for reported absences were not always due to follow-up treatment, and in effect, children with cancer have the highest median absences that *are not* due to treatment when compared to children with other chronic illnesses. Rynard, Chambers, Klinck and Gray (1998) found a similar pattern of absences in children with cancer; mean on-treatment absences totaled 63.54, and the off-treatment absences totaled about half of the on-treatment absences ($m = 31.90$). Both studies suggest that school absences gradually decline after treatment ends; however, neither study explained the rationale behind the absences that were not directly related to treatment issues.

Other research suggests that non-treatment related absences might be due to educational and psychosocial issues, as well as other symptoms, such as fatigue. In a sample of 201 children with chronic illnesses, Weitzman, Klein, Walker & Gortmaker (1986) found a significant

increase in days missed by children whose parents reported psychosocial problems directly pertaining to school and learning ($m = 13.8$ and 18.2 , respectively), than in those without psychosocial problems in those areas ($m = 6.9$ and 6.8 , respectively). Given that multiple school absences are a likely outcome of cancer treatment, it is important to examine the potential outcomes associated with missing a significant number of school days.

Effects of absences on academic achievement. A considerable amount of research has been done on the effects of absence on academic achievement in both healthy students and students with chronic illnesses. School personnel reported that attendance was the biggest obstacle to school performance, as reported by Mancini and colleagues (1989). Epstein & Sheldon (2002) point out the sequential nature of most school curriculums, which results in students with high absences missing crucial opportunities to learn material needed for success later in school. This idea is repeated in several studies. One study on healthy students found that absences and scores for reading and math portions of the California Achievement Test were correlated such that higher absences were related to worse academic outcomes (Epstein & Sheldon, 2002). A similar study found attendance to be a significant factor in predicting achievement scores within a typical school population (Caldas, 1993). When considering a chronically ill population, it makes sense that this effect may be exacerbated because chronically ill children tend to miss more school than their healthy peers, as mentioned above.

In children with cancer, additional negative academic effects (not necessarily related to attendance) have been studied. Several studies have found that those with cancer show decreases in IQ scores and increased academic problems when compared to their healthy peers (e.g. Armstrong & Briery, 2004; Weitzman, Klein Walker & Gortmaker, 1986). Children treated for leukemia are among those at greatest risk for developing long-term cognitive late effects,

particularly those treated with a bone marrow transplant (Armstrong & Briery, 2004). Much of this research has focused on both the immediate and long-term, or late effects, of the treatments. This research has produced mixed results on the types of treatments that may have a negative effect on cognition. Additionally, mixed results regarding variance in the severity of the effects are also noted. For example, mild deficits in IQ were found in children who received both intracranial radiation and chemotherapy compared to healthy peers. However, no differences were found between the healthy peers and those who only received chemotherapy, suggesting that chemotherapy alone may not have a negative effect on IQ (Anderson, Smibert, Ekert & Godber, 1994). One important criticism of the aforementioned studies is that there was no pretesting or baseline data gathered to rule out whether their participants had a lower IQ than their peers before the onset of cancer.

Another study on the effects of chemotherapy found that children treated with the chemotherapy drug Vincristine may experience difficulties with written assignments and motor tasks due to the effects of the drug on the peripheral nervous system (Armstrong & Briery, 2004). Interestingly, motor ability is a major component of most typical intelligence tests used in schools (e.g. WISC-IV and WJ-Cog) as well as in research IQ testing. If a child's motor ability is compromised then it may result in lower IQ test performance if the examiner is not privy to the possibility of motor deficits.

A 1993 literature review by Brown & Madan-Swain explored the research on neurocognitive deficits in children with leukemia. They found that much of the research done on cognitive deficits in children treated with radiation failed to control for absences. Therefore absence from school may be affecting cognition more than cancer does. In addition, a summary of 31 neurocognitive studies done by the same authors found that many of the studies failed to

control for the effect of treatment over time. As such, it is difficult to understand the sequelae of the treatment and whether the effect found on academic achievement or IQ could be a result of attendance. Regardless, it makes sense that having these cognitive and motor issues will affect a child academically, further increasing the need for school attendance as soon as medically possible.

Psychosocial Effects of Absence. Children who are frequently absent not only miss educational instruction, but also face social isolation and psychosocial issues. Children in one qualitative study stated that limited peer contact from absences is quite discomfoting (Bessell, 2001). While a child with cancer is absent from school, several things can change which might make the social aspect of the back-to-school transition exponentially more difficult as the period of absence increases. For example, the mood of a child can be affected by cancer and its treatments. One study found that elementary school children with ALL scored higher on the internalizing scale of the Achenbach Child Behavior Checklist, with higher scores in attention problems, withdrawn, anxious/depressed and social problems subscales, which were all in the clinically significant range (Buizer, de Sonnevile, van den Heuvel-Eibrink & Veerman, 2006). Coming back to school with clinically significant internalizing problems might make it more difficult to maintain current friendships or have negative effects on making new friends. Vannatta, Zeller, Noll & Koontz (1998) found that children with ALL who survived bone marrow transplants had a lower number of best friends than their classmates and had a lower number of mutual best friends than their peers.

During treatment a child's physical appearance often changes in terms of weight loss, fragility, and hair loss, which may affect the way that a child's classmates view him or her. One study found that a child with cancer's peers considered them to be "sick a lot," to "miss a lot of

school," to be "tired a lot" and to have decreased physical appearance and athletic competence (Vannatta, Zeller, Noll & Koontz, 1998).

Grade retention is an issue that many children with cancer face that can have devastating psychosocial consequences. One group of researchers found that more cancer survivors had repeated a grade (20.6%) than did controls (8.5%) (Barrera, Shaw, Speechley, Maunsell & Pogany, 2005). Among the survivors, those with leukemia had the second highest retention. In qualitative studies, children with cancer have voiced that one of their greatest fears is "getting left behind" their classmates and reported that repeating a grade was the worst part of having cancer. In healthy populations, retention is a predictive factor for dropping out of school (e.g. Jimerson, Ferguson, Whipple, Anderson & Dalton, 2002; Ensminger & Slusarick, 1992). Although there is no study that makes this prediction for children with cancer, it is reasonable to assume that the relationship between retention and dropping out of school would be no different for children with cancer.

Interestingly, some other studies have shown that children with cancer do not have greater psychosocial issues compared to their peers (e.g., Noll, Bukowski & Rogosch, 1990). These studies did not include school attendance as a variable, therefore we do not know if children were either attending school or extracurricular activities during their treatment. One study, however noted that the reason for the lack of differences in the groups might be that they have adequate clinical supports in place (Vannatta, Zeller, Noll & Koontz, 1998). Though this evidence is contradictory, one reasonable assumption is that no child's experience with cancer is the same, and that there likely exists significant variation of effects.

Benefits of attending school and regular activities. Attending school or other extracurricular activities, such as oncology camp, during or post-treatment can result in a myriad of benefits for the child with cancer. Examples include: changes from the dependent role the child must play while in treatment, a respite from the sick role (Chekryn, Deegan, & Reid, 1986), and increased opportunities for social engagement and psychosocial growth. The return to school can often signify hope that the child is well and will continue to resume life stability (Ross, 1984). Lansky et al. (1983, p. 121) state that, “just as the success of psychosocial rehabilitation of adult patients with chronic diseases is measured by their return to work, so can the rehabilitation of pediatric patient be assessed by their return to school.”

Acute Lymphoblastic Leukemia (ALL)

ALL is the most prevalent childhood cancer, has the highest risk of infection, the highest event-free survival rates, and is the most-studied of the childhood cancers. Because of these factors, this project will focus on ALL specifically, as opposed to solid tumors or other types of leukemia or lymphomas. ALL is a type of cancer that occurs in the blood, specifically in the white blood cell. It is the most prevalent type of childhood cancer accounting for 25% of all malignancies. This disease prevents the white blood cells from reaching full maturation, resulting in abnormal formation. When formed abnormally the white blood cells cannot perform their main function- fighting infections. Because ALL causes abnormal growth in white blood cells, immunosuppression (the body’s inability to fight infection) is of special concern. Some of the side-effects of treatment (i.e. those affecting the mucous membranes) are immunosuppressant in nature, placing those diagnosed with ALL (as compared to other types of cancers) at the highest risk for infection (Auletta, O’Riordan & Nieder, 1999). It is commonly reported that infection risk is a reason for recommending school non-attendance.

Purpose of the Study

The current practices surrounding school abstention recommendation are not nationally reported and thus, are unknown. The risks of extended absence on a child's academic and psychosocial health are very real and could have serious effects, such as retention, risk for dropout, social delay, mental health issues or cognitive deficits. The benefits of school attendance on a child's sense of wellness and opportunity for social interaction are clear. Although some oncologists recommend that a child attend school as soon as possible after the induction phase of treatment, some hospital's policies have a strict policy to withhold a child from school for an initial nine months, the length of a typical school year. In the United States, there is no written consensus on best practices for school attendance and the general practices of oncologists are unknown. Additionally, there is no written documentation on *why* hospitals have particular policies or why doctors make abstention recommendations. The first purpose of this study is to gain knowledge about current practices of oncologists regarding abstention recommendations. The second purpose is to learn more about what factors contribute to an oncologist's recommendation to return to school (i.e., early in the treatment during intensive chemotherapy versus late in the treatment during maintenance).

CHAPTER 2: METHODS

Survey

A survey was administered electronically to hematologists and oncologists nationwide who were listed in the Children's Oncology Group registry. IRB approval (exempt) was granted prior to the release of the e-survey. Participation was voluntary and responses were anonymous; written consent was waived. The survey queried providers about their practices, experiences and thoughts regarding school reintegration. The survey was created by oncologists and was made up of sixteen multiple choice questions, which were based on observations made in practice. The survey questions are presented in Appendix B.

Two thousand and thirteen surveys were distributed; of those 123 were returned as undeliverable, 16 responders felt that they were not the appropriate person to respond, and eight responders replied that they were no longer practicing. The final number of surveys collected was 316 (17% response rate). Of those, 267 completed all of the questions in the survey.

Variables

The predictor variables were the number of years the oncologist has been practicing (categorical variable defined as "time post-fellowship"), concerns about medical issues (i.e., concerns infection risk and/or ability to tolerate school environment physically) and awareness of the psychosocial and or/academic effects of absence. The outcome variable of interest was when oncologists typically recommended their patients to return to school, measured dichotomously as during "intensive" treatment phases or during "maintenance." This variable was created based on response to the question "Do you feel your practice of reintegration to be early or late," of which the majority defined early as during the more intensive phases of treatment, induction,

consolidation and interim maintenance (38% combined) and 58% reported maintenance to be late.

A dichotomous variable “medical factors” was created by recoding the variable asking which medical factor plays the greatest role in deciding how long a child should remain on homebound (see question 9 in Appendix B). Responses “Potential for infectious exposure at school” and “Child’s ability to tolerate school environment” were recoded as “1 – Medical Factors” and “Parental Concerns” was recoded as “0 – Non-Medical Factors.” Both the nominal variables of academic issues and psychosocial issues were dichotomized based on cut scores determined by the literature and then combined into one variable, “Psychosocial/Academic Factors.” The psychosocial issues cut score was based on Bessel’s (2008) research stating that about 45-55% of children with cancer experience some psychosocial difficulty (e.g., social anxiety, decreased self-worth) upon return to school. Therefore, the variable for this study was dichotomized into either “typical reported incidence of psychosocial difficulty” (including those who answered either 51-75% or 76-100%) or “low reported incidence of psychosocial difficulty” (including those who answered 0-25% or 26-50%).

Similarly, the academic issues cut score was based on the research of Armstrong (1995) who found that the majority (greater than 50%) of children with cancer experience academic difficulty upon school reintegration. Therefore, this variable was dichotomized into either “typical reported incidence of academic difficulty” (including those who answered either 51-75% or 76-100%) or “low reported incidence of academic difficulty” (including only those who answered 0-25% or 26-50%). These two variables were then combined into one dichotomous variable, Psychosocial/Academic Factors based on whether the participant score “typically reported” for either of the two questions. Descriptive statistics are reported, and a binary logistic

regression analysis was employed (via IBM SPSS Statistics 19 binary logistic regression function) to predict the probability that an oncologist would recommend school reentry early (i.e. during either the induction, consolidation or interim maintenance phases).

CHAPTER 3: RESULTS

Descriptive statistics

Descriptive statistics were calculated for all variables of interest and can be seen in Table 2.

Table 2. Frequency Table of Descriptive Statistics

Variable	n	%	M	SD
<i>Time Post-fellowship</i>	267	100	2.59	1.26
Less than 5 years	79	29.6		
5-10 years	51	19.1		
10-15 years	37	13.9		
Greater than 15 years	100	37.5		
<i>Community Type</i>	267	100	3.42	1.291
Metropolitan	28	10.5		
Large City	35	13.1		
Moderate city	71	26.6		
Small City	63	23.6		
Rural area or mall town	70	26.2		
<i>Standardized approach to reintegration</i>	267	100	0.45	0.498
Yes	148	55.4		
No	119	44.6		
<i>Typical treatment phase for reintegration</i>	267	100	3.04	1.022
Induction	30	11.2		
Consolidation	44	16.5		
Interim Maintenance	79	29.6		
Delayed Intensification	0	0		
Maintenance	114	42.7		
<i>Reintegration factors</i>				
Concerns about infectious exposure	38	14.2		
Parental preference	124	46.4		
Child's ability to physically tolerate school	105	39.3		

Variable	n	%	M	SD
<i>Satisfaction with current approach</i>	267	100	0.52	0.845
Very satisfied	41	15.4		
Satisfied	129	48.3		
Neutral	75	28.1		
Dissatisfied	20	7.5		
Very dissatisfied	2	.7		
<i>Re-Entry Consolidated</i>	267	100	.030	.79
Intensive	153	57.3		
Maintenance	114	42.7		
<i>Concerns about medical factors</i>	267	100	.030	.499
Yes	143	53.6		
No	124	46.4		
<i>Report of Academic/Psychosocial Factors</i>	267	100	.036	.59
Report of one	143	53.6		
Report of both	11	42.3		
No report	113	4.1		

The majority of oncologists report that they consider their practice to be early (58%). The factor that plays the greatest role in an oncologist's decision to recommend school non-attendance was the child's ability to tolerate school environment, followed by concern about infectious exposure at school, and parental preference.

There is an approximately bimodal distribution of oncologists who reported completing their residency more than fifteen years ago or less than five years ago. Over 55% of oncologists report that their institution has a standardized approach to school reintegration used by all oncologists at their respective institutions. The phase in which the majority of standard risk ALL patients return to school was maintenance, followed by interim maintenance, consolidation and induction.

Logistic Regression

A logistic regression was conducted to predict early or late school reentry using variables “time post fellowship,” “medical factors” and “academic/psychosocial factors” as predictors. A test of the full model against a constant only model was statistically significant, indicating that the predictors, as a set, reliably distinguished between returning patients to school early or late ($X^2 = 48.06, p < .000, df = 3$). The Hosmer and Lemeshow test of goodness-of-fit for the model was not significant, which means the model was a good fit ($\chi^2 = 8.820, p = .266, df = 7$).

Nagelkerke’s R^2 of .224 indicated a small relationship between prediction and grouping. Prediction success overall was 68.9%. (63.4% of oncologists who recommend return to school early and 76.3% of those recommend return to school late). The Wald criterion demonstrated that both medical factors and level of training made a significant contribution to prediction ($p = 0.13$ and $p = 0.31$, respectively). Academic/psychosocial factor was not a significant predictor.

Odds ratios (OR) for individual variables in the equation, conclude that if oncologists considered medical factors to be an issue, they were four times more likely to return a child to school late. Table 3 shows the logistic regression coefficient, Wald test and Odds Ratio for each of the predictors.

Table 3. Logistic Regression

Predictor	<i>B</i>	<i>Wald χ^2</i>	<i>OR</i>
Medical Factors	1.392	6.212*	4.022
Level of Training	-.232	4.65*	.790
School Factors	-.301	.516	1.433

*** $p < .01$**

CHAPTER 4: DISCUSSION

Description of Practice

The purpose of this study was to gain some understanding of the current practices of oncologists regarding making school re-entry recommendations, which to date are largely unknown. This study found that most oncologists report that their patients return to school during the maintenance phase, which is also the safest phase (in terms of infection) and the phase during which hospital stays and office visits begin to taper. Interestingly, some oncologists suggest their patients return to school during induction, which is the phase that is the most physically taxing on the child. Whereas concern about infection risk was hypothesized to be the primary reason for withholding patients from school (M. Jefferson, personal communication, July 15, 2010), a child's ability to physically tolerate the school environment was the factor most oncologists reported.

Rationale for Practice

The second purpose was to explore the factors that may cause an oncologist to recommend early or late reentry. Again, no research regarding this information is available, to date. Medical factors (which included fear of infectious exposure at school concern for a child's ability to tolerate school environment) carried the majority of the variance for the model; time post-fellowship carried the second largest variance. Reporting typical incidence of academic/psychosocial difficulties among their patients did not significantly predict early or late school reentry practices, which could be expected given that an oncologist's primary job is to treat the child medically.

Interestingly, time post training (years of experience) was a significant predictor, with those with longer time in practice less likely to recommend end-of-treatment (later) return to

school. No research has been found which links level of experience to decision-making; however, one explanation for this finding might be oncologists' knowledge (gained through experience) about a child's ability to tolerate a school environment. For example, perhaps oncologists with more experience are able to recognize the difference between a child's complaints of fatigue and a child's behaviorally driven desire not to go to school (e.g., anxiety related to school, school avoidance).

A limited number of oncologists reported typical incidence levels of both the academic and psychosocial difficulties that many of their patients likely face. Knowledge of this factor should be considered when deciding school re-entry phase, albeit not secondary to medical concerns and, perhaps, penultimate to parental concerns.

Limitations

There were several limitations of this study. One was that oncologists were not given the option to choose academic/psychosocial issues as factors that may influence their decision (as per the question "Which factor plays the greatest role in your decision about how long a child should remain on homebound education?") Available response options included medical factors and parental concerns, but not psychosocial/academic issues. Because of this, we have to infer oncologists' understanding of academic and psychosocial sequelae by their level of reported incidence, with the idea that those with less knowledge of these issues will report lower than typical rates of academic and psychosocial issues among their patients. It is possible that though oncologists may not be aware of the level of academic/social difficulties that their patients face, they may still consider it when making school re-entry recommendations. It is also possible that their particular sample of patients may actually have lower-than-typical levels of such problems. Additionally, though the variables chosen were a good fit for the model, the variables did not

explain all of the variance suggesting more factors are at play. For future survey studies, it would be helpful to have an area where the oncologists can report other potential factors.

Measurement issues were also limitations of the study. Several forced-choice answers may not have accurately captured the questions. For example, when asked whether they consider their practices to be early or late, almost all said that everything before maintenance was early, and only maintenance was considered late. Since there were only two choices, it was unclear whether there was a group who believed that their practice was appropriate.

Implications for Future Research and Practice

Future research could focus on the actual risk of infection and/or inability to tolerate school environment to further guide oncologists' recommendations. Additionally, information regarding the actual practices and typical school re-entry protocols for hospitals would be beneficial in understanding the types of support that children are currently receiving.

The implications of understanding why oncologists make these recommendations can aid future research directed at amelioration of the factors they report, ultimately helping a child return to traditional school such that they can mitigate the negative effects of absence. For example, if medical factors such as physical tolerance is an issue it would be helpful for oncologists to be trained to recognize behaviorally driven issues versus actual somatic complaints.

Another example would be providing the oncologists and their support team graduated school re-entry plans that they can use to reintegrate the child to school while managing their somatic complaints. A pediatric school psychologist or someone who is trained in the interplay between medical, school and child needs would be an optimal clinician to assist with this

undertaking, and several school reintegration plans specifically for children with cancer already exist (e.g., Prevatte, Heffer & Lowe, 2007; Harris 2009).

Conclusion

Extended absence can exacerbate academic, cognitive and psychosocial effects of cancer and its treatment. Therefore, returning to school as soon as possible is typically recommended in the literature. To date, there are no published standards for the optimal phase of treatment for school re-entry, and there are no published typical practices for the same. Oncologists have several reasons for recommending school re-entry later in their treatment including medical factors, such as the potential for infectious exposure and a child's ability to tolerate their school environment. School re-entry timing is also dependent on the amount of time an oncologist is post fellowship. Oncologists are not completely of the typical academic or psychosocial sequelae, as found by this study. For those that are aware, these potential sequelae does not change their re-entry recommendations. More research that focuses on the actual practices of school re-entry recommendation and the assessment of the impact of pain and fatigue on school will need to be done to further understand factors associated with oncologist's re-entry recommendations. Further, more information should be provided to oncologists regarding potential graduated school re-entry plans and behavioral versus somatic complaints such that they can make more informed recommendations. The information found by this study will hopefully add to the currently absent literature base on this topic.

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APPENDIX A: IRB Approval



EAST CAROLINA UNIVERSITY
University & Medical Center Institutional Review Board Office
1L-09 Brody Medical Sciences Building • 600 Moye Boulevard • Greenville, NC 27834
Office 252-744-2914 • Fax 252-744-2284 • www.ecu.edu/irb

FILE COPY

Date: December 3, 2010

2

12/03/10

Principal Investigator: Melissa Rayburg Jefferson, MD
Dept./Ctr./Institute: Pediatrics Hem/Onc
Mailstop or Address: Mailstop 632

RE: Exempt Certification
UMCIRB# 10-0709
Funding Source: Unfunded

12-7-10

Title: "Attitudes and Practices of Providers Regarding School Reintegration for Children with Acute Lymphoblastic Leukemia"

Dear Dr. Jefferson:

On 12/02/2010, the University & Medical Center Institutional Review Board (UMCIRB) determined that your research meets ECU requirements and federal exemption criterion #2 which includes research involving the use of educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures, or observation of public behavior on subjects 18 years of age or older, unless:

- (a) information obtained is recorded in such a manner that human subjects can be identified, directly or through identifiers linked to the subjects; and
- (b) any disclosure of the human subjects' responses outside the research could reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, or reputation.

It is your responsibility to ensure that this research is conducted in the manner reported in your Internal Processing Form and Protocol, as well as being consistent with the ethical principles of the Belmont Report and your profession.

This research study does not require any additional interaction with the UMCIRB unless there are proposed changes to this study. Any change, prior to implementing that change, must be submitted to the UMCIRB for review and approval. The UMCIRB will determine if the change impacts the eligibility of the research for exempt status. If more substantive review is required, you will be notified within five business days.

The UMCIRB Office will hold your exemption application for a period of five years from the date of this letter. If you wish to continue this protocol beyond this period, you will need to submit an Exemption Certification Request at least 30 days before the end of the five year period.

Sincerely, *KWB*

Chairperson, University & Medical Center Institutional Review Board

APPENDIX B: Survey Questions

1. Years since respondent had completed fellowship

<5 years 5-10 years 10-15 years > 15 years

2. Type of community from which most patients originate

Metropolitan Moderate City Small City Rural or Small
Town

3. Is there a standardized approach to school reintegration used by all the oncologists within your institution?

Yes No

4. Do you have a formal program in place for all of your patients in which designated support staff are responsible for coordinating school reintegration efforts?

Yes No

- a. If so, who is the individual primarily responsible for coordinating school reintegration efforts?

5. Who do you involve in your school reintegration preparation? (check all that apply)

Physician Nurse Social
Worker Teacher Patient Family

6. During what phase of therapy do the majority of your standard risk ALL patients generally return to school?

Induction Consolidation Delayed
Intensification Interim
Maintenance

7. During what phase of therapy do the majority of your high risk ALL patients generally return to school?

Induction Consolidation Delayed
Intensification Interim
Maintenance

8. Would you consider your practice of reintegration to be early or late reintegration?

Early Late

9. Which factor plays the greatest role in your decision about how long a child should remain on homebound education?

Potential for infectious exposure at school Child's ability to tolerate school environment Parental Concerns

10. Do you instruct parents to keep children home from school during periods of neutropenia?

Yes No

11. In general, do you instruct patients to have a child wear a mask to school during periods of neutropenia?

Yes No

12. When your patients are receiving homebound instruction, on average, how many hours per week of formal instruction do they receive?

0 hours 1-5 hours 6-10 hours 11-15 hours <15 hours

13. In what percentage of patients do you estimate that you encounter psychosocial difficulty with school reintegration?

0-25% 26-50% 51-75% 75-100%

14. In what percentage of your patients do you estimate encounter academic difficulty as a result of receiving homebound instruction as opposed to traditional classroom instruction?

0-25% 26-50% 51-75% 75-100%

15. How satisfied are you with your current approach to school reintegration?

Very satisfied Satisfied Neutral Dissatisfied Very Dissatisfied