

"Back to school" - An evaluation of a re-entry program for school-aged children with cancer

By Mary-Lou Ellerton and Cathy Turner

Abstract

This study describes an evaluation of a program to help eight to 12-year-old children with school re-entry after initial diagnosis and treatment for cancer. The effects of the program on the children's classmates' knowledge about cancer and attitudes towards the child are reported. The self-reported coping strategies used by the returning children for management of major concerns about school re-entry are described. Overall, classmates were well informed about cancer and described mainly positive feelings towards the returning children and these feelings did not change significantly as a result of the program. Nevertheless, the notion that cancer is always a fatal disease was persistent and many classmates reported personal fears and vulnerabilities associated with cancer. Returning children described teasing as a major concern and reported very individual patterns of coping with teasing. Implications for practice and research are presented.

Increasing numbers of long-term survivors of childhood cancer have kindled interest in devising ways of helping newly diagnosed children resume their schoolwork and social lives in the classroom. Many of these children, who a few years ago would have had a life expectancy of only several months, now have a good chance of surviving well into adulthood (Komp, 1989; Moore, Glasser & Ablin, 1987). Many more children with cancer are now returning to school. This report describes the findings of a project evaluating a program to help children with cancer on their return to school after diagnosis and initial treatment.

Today, 60 per cent of children diagnosed with cancer will be cured of their disease (National Cancer Institute of Canada, 1989). The objective of caring for children with cancer has shifted from one of preparing the child and family for a peaceful death to helping them cope with the challenges that are inherent

in living with a chronic illness. Some of the most commonly reported concerns of these children centre around resuming school activities (Davis, 1989; Kagen-Goodheart, 1977; Ross & Ross, 1984; Sachs, 1980).

The return to the classroom represents an opportunity for children with cancer to regain a sense of normalcy and self-confidence in a developmentally challenging environment. At the same time, the re-entry period is often fraught with difficulties for the returning child. These include worry about teasing from classmates (Henning, 1985; Ross & Ross, 1984), sensitivity to changes in their appearance (Chekryn, Deegan, & Reid, 1987; Kagen-Goodheart, 1977), difficulty keeping up with schoolwork associated with fatigue and frequent absenteeism (Barbarin & Chesler, 1983; Chekryn, Deegan, & Reid, 1987). Research has determined that children who do not return to their classroom early in their illness have more problems with reintegration (Katz & Jay, 1984).

The child's return to the classroom also poses challenges to teachers and classmates who are often uncertain about how they can best help the child. Interviews with teachers have revealed that their lack of knowledge about the child's disease creates uncertainty about the demands they can place on the child and the amount of discipline they should impose (Barbarin & Chesler, 1983). Teachers also report concerns about providing appropriate opportunities for social and cognitive development and about coming to terms with their own feelings about cancer in children (Chekryn et al, 1987).

Classmates of school-aged children with cancer have been described as capable of providing support to a sick classmate but as tending to become distanced from the child who has frequent or prolonged absences from school (Davis, 1989). In addition, misunderstandings by classmates about contagion and cancer (Sachs, 1980) and personal feelings of fear and vulnerability (Chekryn et al, 1987) have interfered with peer acceptance of the returning child. Nevertheless, significant increases in school children's knowledge about cancer and interest in interacting with the returning child have been reported from a workshop for classmates (Benner & Marlow, 1991). Canam and Elliot's (1985) peer helper program has been reported to contribute to the self-esteem and acceptance of adolescents with chronic illnesses.

The literature contains numerous reports of programs designed to

"DE RETOUR À L'ÉCOLE" - ÉVALUATION D'UN PROGRAMME DE RETOUR EN CLASSE POUR LES ENFANTS D'ÂGE SCOLAIRE ATTEINTS DU CANCER.

ABRÉGÉ

Cette étude décrit l'évaluation d'un programme visant à aider les enfants âgés de huit à douze ans à retourner en classe après un diagnostic du cancer et son traitement initial. Elle rapporte les effets du programme sur les connaissances des camarades des jeunes malades sur le cancer ainsi que sur leurs attitudes vis-à-vis des patients. Elle fait la description des stratégies rapportées par les jeunes patients pour régler les principaux problèmes que pose le retour en classe. Dans l'ensemble, leurs camarades étaient bien informés au sujet du cancer et ils exprimaient des sentiments généralement positifs à l'égard des enfants qui retournaient en classe et ces sentiments ne changeaient pas de façon significative à la suite du programme. Toutefois, il reste que le cancer est encore perçu comme une maladie mortelle dans tous les cas et que maints camarades parlaient des angoisses et de la vulnérabilité qu'ils ressentaient face au cancer. Les jeunes malades qui étaient retournés en classe se plaignaient surtout des taquineries et mentionnaient les stratégies très personnelles qui leur permettaient d'y faire face. L'article présente les implications de l'étude au niveau de la pratique et de la recherche.



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facilitate the child's return to school (Baskin, Saylor, Furey, Finch, & Carek, 1983; Benner & Marlow, 1991; Goodell, 1984; Katz, Rubinstein, Hubert, & Blew, 1989). Some are anecdotal, others are more systematic accounts written from the perspective of the needs of classmates. Very few studies have focused on how programs affect classmates' perceptions about cancer and its treatment and the fears and concerns of the returning child.

"Back to School" is an educational program developed by the British Columbia Division of the Canadian Cancer Society to meet the needs of classmates when a child newly diagnosed with cancer returns to the classroom. This study was undertaken by the Nova Scotia Division of the Canadian Cancer Society to evaluate the effectiveness of the program in improving classmates' knowledge and attitudes about cancer and children with cancer, and to determine the concerns and coping behaviours of returning children. The objectives of the study were:

1. to examine the effects of the program on the child's classmates' knowledge of cancer and cancer treatment effects;
2. to determine the effects of the program on students' attitudes towards children with cancer;
3. to examine the fears and concerns of children with cancer about their return to the classroom;
4. to identify coping behaviours used by newly diagnosed children with cancer upon their return to school.

Method

Subjects

Three children newly diagnosed with cancer and their 64 classmates comprised the study sample. The children with cancer were selected by convenience, provided that they were of normal cognitive development, English speaking, had no major sensory or motor deficit, were expected to return to school within one month of being inducted into the study, and attended a school within a one-and-a-half hour drive from the Izaak Walton Killam Hospital for Children where the study took place. The three children were girls, aged seven, nine, and ten years. Three eligible children were not admitted to the study: One child died before returning to school, one child's parent refused to allow him to resume school until completion of his treatments. The third child said that she did not anticipate problems with school re-entry. The classmate subjects were 19 grade five children, 18 grade four children, and 27 children in grade two. The average age of children in the grade five class was 10.0 years, in the grade four class, 8.8 years, and in the grade two class, 7.4 years.

Procedure

The children with cancer were interviewed approximately one week before their return to school using a semi-structured interview format and a questionnaire. The interview explored with the children their usual feelings about school, their attitudes about returning to school, and any particular concerns they had about returning to school. The interviews were audiotaped and transcribed. The same children were interviewed again at a clinic visit four to six weeks later about how they had been managing at school and any difficulties they had experienced. At that time, the children completed the 25-item self-report Children's Coping Strategies Inventory (Ryan, 1989) in response to their greatest concern about re-entry. The instrument measures, on a four-point scale, the frequency and effectiveness of children's coping strategies in response to a major stressor.

The internal consistency of the SSCI as measured by Cronbach's alpha was 0.76 for the frequency scale, 0.77 for the effectiveness scale, and 0.79 for the total scores. Construct validity was demonstrated using the known groups method in which children with a chronic illness had significantly lower coping scores ($p = 0.0078$) than a control group of children.

The classmates of the children completed a questionnaire immediately before attending the "Back to School" class. The questionnaire was comprised of 20 questions divided into three subscales: The section which assessed knowledge about cancer and cancer treatment consisted of 10 true-false questions based on the objective material contained in the class. In addition, the children responded on a Likert-type scale to six attitude pairs (eg, feel "OK" or good about him/her - do not feel "OK" or good about him/her) that might apply to a classmate's approach to a returning child. The scale is a 100 mm line with two anchor points, (0 = feel very worried, for example, to 100 = do not feel worried at all). A third section asked for demographic information. The questionnaire was developed by the authors from the

classroom presentation content and from a questionnaire developed by Baskin et al., (1983) for use with teachers attending a re-entry workshop for school personnel. The validity and reliability of the questionnaire have not been established. The children completed the questionnaire immediately prior to the classroom presentation and again four weeks later.

The program

The program is prepared as a manual (Canadian Cancer Society, 1986) written to guide a volunteer through the planning and implementation of a classroom presentation. The planning component consists of sections on understanding the impact of a cancer diagnosis on families, how to talk to parents in a supportive way and how to prepare the presentation together with the child and family in a way that addresses the family's particular concerns about the child.

The implementation component is a classroom presentation which begins with a simple discussion of the child's treatment. Common myths about causation and contagion are clarified. The physical changes and limitations brought on by the child's disease and particular treatment are described. Finally, the need for the child to participate as fully as possible in classroom and social activities and to feel accepted and normal are discussed. The children are encouraged to ask questions and to devise ways that they can help the returning child participate in everyday school activities according to the child's strength, motivation, and physical restrictions.

After the class, the volunteer views with the teacher a videotape entitled "Coping with Chronic Illness in the Classroom" (Cincinnati Hospital Medical Center, 1986), designed to help schools effectively respond to students with severe chronic illness. The tape consists of a series of vignettes which explore such topics as family dilemmas surrounding a child's return to school, the discomfort that school personnel may experience when the child first returns and the satisfaction that comes from collaborating with families, individualizing programs of social and academic activities for medically fragile children, working effectively with siblings and, finally, helping classmates respond appropriately should the death of a classmate become inevitable. Teachers also receive a booklet published by the American Cancer Society (1990) called "Students with Cancer: A Resource for the Educator". Teachers are given the work phone number of the presenter and invited to call with any concerns they had about the child. Telephone contact is maintained with the teacher at two-month intervals for the remainder of the school year to monitor the child's progress in school.

The need for volunteers to administer the program, volunteers who were familiar with the particular needs of the children and families for information, physical care, and support to administer the program led to the recruitment of registered nurses on the oncology unit at the study hospital. The returning children were asked to choose from four nurses who volunteered for the program, the person they would most like to come to their school. Nurses who volunteered participated in a three-hour training session to become familiar with the objectives and content of the program. The nurses used their days off for the project and were not reimbursed.

Results

Analysis of variance was used to test for an increase in the mean scores for knowledge about cancer and cancer treatment in the three groups of participating children. No significant improvement in scores was found for the overall group ($F = 1.984, p \leq 0.16$). Mean scores for knowledge for the overall group were 8.09 ($sd = 1.22$) on the pre-test and 8.42 ($sd = 1.34$) on the post-test. The scores for both groups of older children improved from pre- to post-testing, but only the changes for the grade five children were significant ($F = 9.81, p \leq 0.003$) [See Table One]. The scores for the younger children actually decreased from 8.24 ($sd = .77$) at pre-test to 7.76 ($sd = 1.05$) at post-test. The project was designed for and pilot-tested on eight to 12-year-old children. Because of difficulty recruiting children who met the specific age requirements for the study, the group of younger children was admitted. It appears that the estimate of the level of difficulty of the instruction and testing was more appropriately targeted for the older children (ie, grades four and five).

Overall, the children demonstrated positive attitudes towards children with cancer. The mean attitude scores measured in per cent at the time of pre-testing were 77.2% for the grade five children, 73.8% for the grade fours, 72.2% for the grade twos and 74.2% for the overall group. One way analyses of variance revealed no significant improvement in attitude scores for any of the individual groups or for

the overall group (Table Two). There was a slight decrease in the attitude scores of the grades four and five children. In a recent evaluation of a school re-entry program, Benner and Marlow (1991) also found no significant change in classmates' concerns about the returning child. They attributed this result in part to the individual differences in the appearance and health status of the returning child. By the time one of the children in our study was able to return to school, she had lost almost 30 pounds and appeared very ill. Her slow progress and physical deterioration may have contributed to the concerns reflected in her classmates' attitude scores. However, the other child whose classmates' attitude scores decreased had a relatively uneventful illness-free period between diagnosis and her return to school.

Multiple regression analysis revealed that neither gender nor previous associations with persons with cancer influenced the classmates' knowledge about cancer or attitudes towards the child with cancer.

The children's responses to the interview questions were content analyzed. All of the children reported that they usually like school. Two of the girls expressed fear of teasing as their biggest concern about returning to school, and afterwards, all three children identified teasing as the worst aspect of the re-entry process. In spite of the program's focus on sensitizing the children to the child's vulnerability and need to feel normal, all three girls reported being teased more than once on their return. One child reported verbal taunts and wig pulling. Another had her cap pulled off twice within a week of her re-entry. Nevertheless, all three children said they enjoyed school and attended every day they were able.

The children's responses to the Schoolagers' Coping Strategies Inventory revealed very individual patterns of coping with teasing. All three children reported using more than 10 of the 25 items and there was little overlap of items between subjects. Table Three shows the strategies reported by each girl as ones that she used "a lot" and the corresponding effectiveness of each of those strategies. The strategies the children reported using a lot or most of the time were also the ones identified most often as effective, and those the children reported using occasionally or not at all were rarely reported as helpful.

Discussion

Classmate's knowledge

The results suggest that the children's classmates were relatively well informed about cancer prior to attending the program. Many of the classmates were familiar with the rapid growth of cancer cells, the non-contagious nature of cancer, and some of the side-effects of chemotherapy. At the same time, more than half of all classmates believed that the statement "Children with cancer can live for a very long time" was false at the time of pre-test. That same pattern was still apparent in over half of the younger children and nearly a third of the older ones at the time of the post-test. The only attitude that showed a significant change in the overall group was an increase in feeling sorry for the returning children. In spite of the instruction and overall improved test scores, it appears that the notion that cancer is always a fatal disease is firmly held by many children. Perhaps this is a reflection of a general societal belief about cancer and one which illustrates how the association of cancer with death is entrenched in children as young as seven years.

Teasing
The major concern of returning children was teasing from classmates. We attempted to offset the likelihood of teasing by helping classmates appreciate the child's point of view but the program was not very effective in this respect.

The incidents of teasing that did arise were dealt with conventionally by teachers who lectured the offenders. Other researchers have also described this problem. Ross and Ross (1984) concluded from their research with leukemic children that no reliance should be placed on strategies to change other children's reactions to the returning child. We advised the last child admitted to our study, as well as her parents and teacher, of the near certainty

Table One: Change in knowledge scores

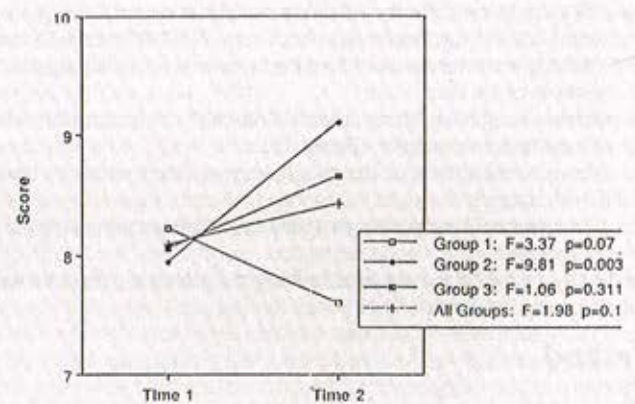


Table Two: Changes in attitude scores

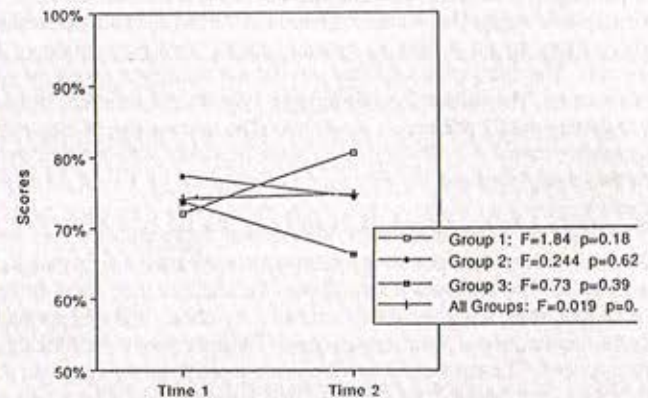


Table Three:

CHILD ONE			CHILD TWO			CHILD THREE		
Strategy	Frequency	Effect	Strategy	Frequency	Effect	Strategy	Frequency	Effect
Cuddle a pet	3	3	Try to forget	3	3	Be by myself	2	3
Get mad	2	2	Watch TV	3	3	Cry, feel sad	2	3
Think about it	2	1	Daydream	3	3	Fight	2	1
Watch TV	2	0	Talk to Someone	3	3			

Frequency: 0 = Not at all; 1 = Once in a while; 2 = A lot; 3 = Most of the time

Effectiveness: 0 = Never do it; 1 = Doesn't help; 2 = Helps a little; 3 = Helps a lot

of teasing. When she was teased, the child was able to protest and report the incident herself to her teacher and family, although she also reported crying and feeling sad about incidents of teasing. In place of a punishment, the school's resource teacher viewed the film "Why Charlie Brown, Why?" (Schulz, 1989) with the offending children and addressed their misunderstandings about cancer. The effectiveness of non-punitive interventions such as this one are deserving of further study.

Classmates' vulnerability

Although the program stressed the fact that cancer is not contagious and that it is safe to play with children who have cancer, several classmates in all three schools expressed their sense of vulnerability to cancer and death by describing personal illness experiences, cancer risk factors or past associations with persons with cancer. A review of children's literature on cancer revealed not a single publication which meets the special needs of well school-age children for age-appropriate information about cancer and improving prognoses for many children with cancer. Easier access to age-appropriate information may be effective in reducing children's fear and misunderstandings about childhood cancer.

The community health nurse

Follow-up calls from the researchers to parents and teachers about the returning child's school adjustment revealed many concerns about the child which arose after the classroom presentation. A meeting with the community health liaison nurse at the hospital revealed that few community nurses are either experienced or well prepared in pediatric oncology nursing. As a result of the study, we have met with provincial community health nurses at their annual conference to acquaint them with the project. We have decided against a large-scale educational effort for the nurses in favour of involving the community health nurse in the child's re-entry on an individual basis. A manual prepared for community health nurses provides information about childhood cancer and treatment as well as the issues associated with school re-entry at a time when that information is useful to them.

Teachers' concerns

Although we originally planned to view and discuss the videotape for teachers with the child's individual teacher, every teacher in the first school we visited attended the presentation. We have continued this format and the pattern repeats itself. Teachers have expressed their feelings of shock at a cancer diagnosis, and sadness and regret over misunderstanding a child's symptoms. They have asked questions about prognosis, the child's permissible activities and helping the siblings they see as forgotten, as well as


what to say and do for the child's classmates if the child's condition should deteriorate.

Children's participation

During the period of data collection, three children who were eligible for study declined to participate. One of those children subsequently approached a nurse volunteer with a request to visit her classroom. Since the completion of the study, the nurses have made four more school visits and no child or parent has declined an invitation.

Summary

One of the most important aspects of every young child's life is the school experience. All of the children in this study were enthusiastic about their re-entry. At the same time, all three children reported incidents of teasing on their return to school. The children's classmates performed well on conventional questions about cancer and cancer treatment but the program did little to demonstrate a change in the classmates' knowledge about cancer and attitudes towards children with cancer. Nor was the belief that cancer is a fatal disease altered significantly by this intervention.

Although the classmates performed well overall on the objective questions, they brought to the presentation their vulnerabilities, uncertainties, and curiosities about the returning child. Further research into school-age children's knowledge and concerns about cancer and cancer treatment will assist in the development of programs that are consistent with the children's needs for information and the development of positive attitudes towards cancer and the returning child. The finding that the returning children had developed patterns of coping which they considered to be effective in managing stressful school-related situations deserves further study. As well, the successful reintegration of the child with cancer involves the coordinated efforts of key players including families, teachers, and community health nurses. Lastly, re-entry programs for children with cancer should be considered as one component of the education of young children to the needs of children with cancer who are returning to school. All programs must be accompanied by efforts to increase public awareness of the advances in medical treatment that have markedly improved survival rates for those having childhood cancer. 

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