
THE SCHOOL EXPERIENCES OF CHILDREN WITH CANCER:
VIEWS OF PARENTS, EDUCATORS, ADOLESCENTS & PHYSICIANS

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PART 1. INTRODUCTION

Medical advances that have extended the lifespans of children with cancer, and that have permitted some children to be cured, have given rise to a set of "second generation" problems. Now that more children with cancer are living, and living longer, they and their families must deal with problems of "re-entry" (Kagen-Goodheart, 1977). The concept of re-entry refers to the ways in which children and their families attempt to return to relatively normal family and community functioning after a diagnosis of cancer. For the school age child, re-entry to school is one of the most important and formidable paths to normalization.

To provide a sensitive, comprehensive, and credible account of the school experiences of children with cancer is a difficult and challenging task. To proceed without recognizing the diversity of those experiences, as though the lives of all children with cancer were alike, is misleading. Most importantly, cancer is not a single disease, but a group of related diseases with somewhat unique features, treatments and courses of development. These basic differences have implications for the degree of life-threat and disruption children and families experience. Because children also differ in personality, in behavior, and in life circumstances, even when they have similar forms of cancer their reactions to the illness may vary greatly.

What dimensions best describe the varied school experiences of children with cancer? In addition to socio-demographic factors often recognized as the base of social stratification (e.g., income, education, race, sex, etc.), a host of other variables seem to be influential. These include characteristics of the child (personality structure, age at diagnosis, current grade level, and stage of cognitive and emotional development), and systemic characteristics of the family (resources,

role differentiation, relationship with the school), the medical system (available medical treatments, sensitivity of staff, linkage to the school) and the school (size, institutional resources, experience with chronic illness, supportiveness).

Characteristics of the Child

A number of characteristics of the child have an impact on how the diagnosis and treatment of cancer is experienced, and how re-entry to school is managed. The child's particular personality and the ways in which he or she copes with the illness is one important factor. Of course, the child's approach is by no means independent of the family's, and the typical coping patterns a young person learns are related to those of a particular set of parents, in a particular family constellation, embedded in a particular social status. Some children feel quite fragile and vulnerable, and wish to keep their new medical situation a secret from peers and educators, at least insofar as possible. Other children are prepared to "go public", and to share widely information about their situation. Individual levels of courage and anxiety, of denial and optimism or pessimism, also affect the child's view of the potential for normal relations in school. In addition to these intrapersonal variables, other factors such as the age of the child, and the specific diagnosis, may have substantial impact on future experiences, in and out of school.

Chronological age influences the experience of childhood cancer in at least four ways. First, the age of the child at diagnosis often is associated with the type of cancer and the prognosis (Potter, 1974). For example, Retinoblastoma, Wilm's tumor and Neuroblastoma are most likely to occur in very young children - at a median age of less than 3 years. Bone cancers (sarcomas) are more likely to occur in pre-pubescent and adolescent children. Although the link between age and leukemia, the most common form of cancer among children, is not as clear cut, most children diagnosed with leukemia are between the ages of 2 and 12. Moreover, when

leukemia occurs outside this age range the prognosis for long-term survival is more pessimistic. Second, chronological age is related to levels of cognitive, emotional and moral development, and to the primary developmental tasks confronting the child (Dill, 1978; Maccoby, 1980). These attained capacities and age-specific tasks have a significant influence on the aspects of the child's life most disrupted by treatment, and on the meaning or interpretation the child and family make of the entire illness experience (Fraiberg, 1959; Ginsberg and Opper, 1969). A third way in which chronological age may affect the experience of childhood cancer is derived from the physical plasticity and emotional resiliency observed in very young children. We can speculate that the long-term psycho-social effects of cancer may be less severe when children are diagnosed at an early age, because young children themselves may be more flexible and consequently better able to accommodate to life changes resulting from cancer. Currently there is not a strong empirical basis for this assertion although several studies in progress should illuminate the link between age and the psychological effects of cancer and its treatment. Fourth, age also is associated with several normal transitions in the demands the organized adult world makes of young people. With regard to students in particular, age is related to changes in schooling from pre-school to elementary school, from elementary to junior high school, and from junior to senior high school.

Transitions in schooling may be stressful under the most normal circumstances. They often are characterized by feelings of ambivalence, combining optimism and concern about whether one is up to the unknown challenges inherent in the new situation. Each transition presents a unique set of tasks to be accomplished and stressors to be faced. For the child in kindergarten, the transitional tasks include separation from parents, acceptance of a new socializing adult, accommodation to the cognitive demands of school and the interpersonal demands of peer interaction, and

acclimation to a new set of physical surroundings and routines. The transition from elementary to junior high school focuses largely on issues related to the student's physical development, relationships with a larger peer group and personal autonomy and integrity. The transition to high school brings with it a different set of concerns. At this stage of development a foundation is laid for the adoption of roles related to achievement and mature social relationships, as well as the establishment of life plans which may carry children into adulthood (Erikson, 1968).

Each of these transitions is made more difficult by the diagnosis of illness, by the uncertainty and disruptiveness accompanying the treatment of cancer, and by the reactions of others. The high physical, emotional and temporal cost of cancer, and the intensive procedures required for its treatment, add to the already difficult developmental tasks which children, adolescents and young adults must perform during their school years (Kellerman & Katz, 1977).

Characteristics of the Family

Differences in children's experiences in school also are related to family characteristics. Not only does each child respond uniquely to the disease and its sequellae, so does each family and each family member. Families have characteristically different internal role divisions, and different tasks assigned to mothers, fathers, children with cancer and other older and younger siblings. Some families cope well with the shocks of childhood cancer and its aftermath; some barely survive. Moreover, some cope actively and publicly, reaching out to friends and neighbors for support; others cope privately, keeping feelings and problems to themselves. Some families deny or minimize the impact of the disease; others may become anxious and attentive to every potential problem, perhaps even spoiling the child. A family committed to managing its problems privately, and reluctant to share the fact of childhood cancer with friends and neighbors, is unlikely to be very open

with the school - principals, teachers and classmates. A family committed to gathering external resources, to sharing their new reality with friends, may become very active in informing the school and in seeking help from school personnel as well. A family committed to normalization may respond to many issues differently than a family concerned with special attention and special adjustments.

Family members' prior experiences with schooling also may be relevant for the quality of school re-entry of the child with cancer. Their educational backgrounds, dispositions toward formal education and historic relationships with the school staff all may affect the way they deal with their child when school-related problems occur. In addition, they may affect parents' and children's abilities to and interests in raising issues, expecting positive responses and otherwise entering negotiations or joint planning with the school staff.

Characteristics of the Medical System.

Qualities of the medical care organization in which the child is treated may have a significant effect on the child's prognosis, treatment duration, and quality of life during and following treatment. Recently, tremendous strides have been made towards the development of more effective treatments for a variety of cancers. For example, new drugs have been developed and existing drugs have been used in novel combinations or at higher levels to achieve more effective arrest of cancerous growth. Improvements in the use of surgical techniques have been combined with the use of other therapies. Developments in radiation therapy have made it possible to control more precisely the areas of irradiation, and thus enable radiologists to focus more intensely on the cancerous site(s). Developments in the use of bone marrow transplants is another promising area of clinical research offering new hope to leukemic patients. In addition, there is an increasing tendency in the management of childhood cancer toward individualization with respect to diagnostic and treatment

procedures (American Cancer Society, 1982).

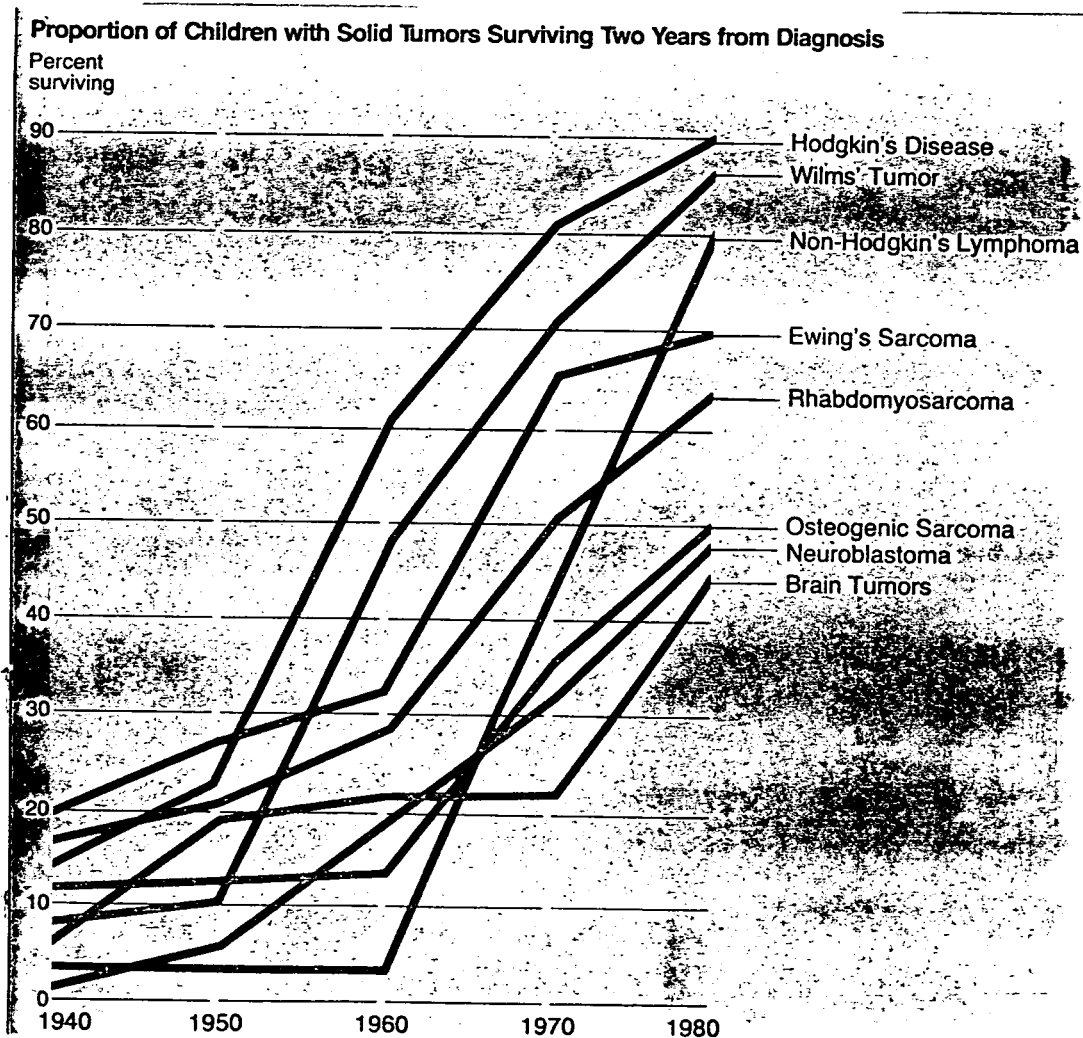
For the most part, these treatment innovations are available in major cancer centers around the country, but are less likely to have been disseminated to smaller community hospitals. Therefore, the experiences of children in large childhood cancer research centers are likely to be different from the experiences of children in hospitals which are not a part of this network. To the extent that these treatment innovations are available, they have resulted in dramatic increases in rates of survival. The American Cancer Society describes the progress in this way:

"The following fourteen cancers, a few decades ago had very poor prognoses -- today they are being cured in many cases, predominantly because of chemotherapy advances: acute lymphocytic leukemia, acute myelogenous leukemia, Hodgkin's disease, histiocytic lymphoma, Burkitt's lymphoma, nodular mixed lymphoma, Ewing's sarcoma, Wilms' tumor, rhabdomyosarcoma, choriocarcinoma, testicular cancer, ovarian cancer, breast cancer, osteogenic sarcoma. Other cancers are being more effectively controlled than in the past.

An outstanding example of progress is the improvement in the management of Hodgkin's disease (a cancer of lymph glands in predominantly young adults). Better disease staging in certain cases, more precise application of new and improved x-ray therapy and/or a combination of four cancer drugs has resulted in remarkably improved survival. In less than 10 years, the five-year survival rates for early cases rose from 69 to 90%, and from 10 to 70% for advanced cancers of this type" (American Cancer Society, 1982, p.5).

Figure 1, prepared by the National Cancer Institute, shows the change in the 2-year survival rates, differentiated by each type of children's cancer. Progress is evident in the upward trend for each illness, suggesting significant improvements in 2-year survival rates between 1960 and 1980.

Figure 1



*Source: National Cancer Institute, 1981.

In addition, the five year survival rates for children with cancer have increased considerably for children diagnosed between 1970-1973, as compared to children diagnosed between 1960-63. From the early part of the 1960s to the 1970s, the five year survival rates for children diagnosed with the most common form of childhood cancer, acute lymphocytic leukemia, improved from 4% to 34%. For the second most common, brain or glioma cancer, 5-year survival rates improved from 48% to 59%; and for the third most common, neuroblastoma, comparable rates improved from 25% to 40%. On the other hand, for some types of cancer the outlook is less positive; the data presented in Table 1 show clear differences in the 5-year survival prospects of children with bone cancer (30%), retinoblastoma (85%) or cancer of the lymph glands (90%). Although no survival rate can be described as acceptable until it is 100%, the long-term and short-term outlook for children with most forms of cancer has become considerably brighter.

Table 1
Percentage of children with cancer who
survive 5 years after diagnosis*

<u>Cancer Group</u>	<u>% Survival at 5 years</u>
Bone Cancer	30
Acute Lymphocytic Leukemia	34
Neuroblastoma	40
Glioma Cancer (brain)	59
Wilms' Tumor (kidney)	70
Retinoblastoma (eye)	85
Hodgkin's Disease (lymph glands)	90

*American Cancer Society, 1982.

Characteristics of the School or School System

Schools vary in several ways, some of which have important implications for the experiences of the child with cancer. For example, size may matter. In small schools, many children are likely to be known by most students and teachers. Often such familiarity is expressed in terms of concern and support for the student with cancer in a way that is less probable in a large and more anonymous school. On the other hand, in large schools and school systems the availability of resources such as a health program, with nurses, special educators, hospital liason staff, etc., can contribute to the well-being of sick children.

Changes in the educational environment, resulting from enlightened school policy and federal legislation, also hold out significant promise of improving conditions for seriously ill children. The most critical development has been the passage and implementation of PL 94-142, the Education for All Handicapped Children Act. As most educators know, this law effectively mandates that all children, regardless of handicapping condition, have access to public education in the most appropriate form, and in the most normal and least restrictive environment. In addition, several states have passed legislation which further improves the rights of access to public education of handicapped children. Historically, when school programs existed for children with life threatening illnesses such as cancer, they focused on providing home-based education, remedial tutoring, or brief homework review sessions. Too often children with cancer were ignored and written off, especially when they were out of school for extended periods or when death seemed imminent. The spirit of the law now requires that schools create a viable range of alternative instructional opportunities for students who are unable to particiapte fully in the typical classroom.

Compliance with these new laws and local policies create dilemmas for some classroom teachers trying to deal with children with diverse physical capacities.

Consequently, teachers must learn to adapt their traditional teaching methods and goals to accommodate ill children, without over-compensating for their handicaps and infantilizing them. For many teachers, formal education or retraining may be impracticable. And as a result, the only preparation they receive may come in the form of on-the-job training. In these cases teachers are called upon to be flexible and willing learners, reaching out with uncertainty to discover and deal with the specific needs and strengths of the chronically ill child.

In all, many factors probably contribute to the diversity of experiences children with cancer have when they return to school. The nature and severity of the specific illness and treatment regimen is likely to be a determinative factor. In addition, the child's own outlook, dependent perhaps upon developmental level, and the character of the medical treatment facility, the family's orientation and the school staff's outlook all play a part. Because of the growing hopefulness and complexity of medical advances, it is impossible to make direct inferences about a child's school future today on the basis of experiences a decade ago. Death is no longer a certainty. With extended life, attention to the quality of life will require more careful consideration of the roles and impacts of the hospital, the family and the school on the experiences of children living with cancer.

Prior Research

The re-entry to school by the child with cancer presents complex issues for all the people and institutions involved. This report explores some of these issues from the vantage points of parents, school staffs, medical staffs, and adolescents with cancer. It describes some of the real-life dilemmas created by school re-entry, and some of the ways individual actors and institutions handled those dilemmas. As we have noted, some of the potential problems children with cancer face as they and

their families attempt to stabilize and normalize their lives are a direct function of the illness and treatment itself. Numerous physicians, medical researchers and other observers have argued that children with cancer can be expected to have a variety of physical problems post-diagnosis and during or after treatment. As a result of almost universal chemotherapy and radiation therapy, children should experience hair loss, weight loss and gain, and fatigue to the point of exhaustion. Depending upon the nature and course of their illness, they also may experience occasional or continual hospitalization. Those who must have surgery, may have the results visible in the form of limb amputations. All these treatments have physical impact upon the child; they also have psychological impact!

In a recent study reported by Deasy-Spinetta & Spinetta (1980), teachers of 42 school-age cancer patients completed questionnaires describing the behavior and affect of their typical students, and of students with cancer. Importantly, teachers did not rate students with cancer as different from control subjects (i.e. students without cancer) on characteristics such as willingness to attend school, play habits or dependency. However, teachers did report that students with cancer attended school less frequently, had greater difficulty concentrating, and had less energy than their peers. Moreover, they described these children as "inhibited, less active, less willing to try new things, and less likely to express either positive or negative emotions" (Deasy-Spinetta & Spinetta, 1980, p.89). In another study, O'Malley, Foster, Koocher, & Slavin (1979) studied 117 long term survivors of childhood cancer, to determine the level of adjustment problems and psychiatric symptoms in that group. Many of these young adults (some still students) had mild adjustment problems, resulting from difficulties in social relations, anxiety, and depression. There is a double message in most of these and other reports: one is that psychological and adjustment problems do occur; the other is that they do not occur often in very serious terms.

Concern about these issues, and for these children, has led some observers to overstate their seriousness, and to suggest that many or most children experience serious problems. For example, Moore & Triplett state that the "child with cancer suffers from delayed development (1980, p. 265)," implying that this is typical or usual. Others have drawn attention to children's potential psychological maladjustment (van Eys, 1977; 1977a), potential family dysfunction or dissolution (Kaplan, et al., 1973; Lansky, et. al, 1978; Share, 1972), and even school phobias (Lansky, et al., 1975; Futterman & Hoffman, 1970). While such concern is important, too strong a focus on the negative or pathological appears quite incorrect (Kellerman, 1980; Tavormina, et al., 1976); it also may help build stereotypes and create new barriers to adjustment.

Not only may researchers exaggerate these potential problems; so may parents. If worried parents buffer their children overmuch, overprotecting them, youngsters may receive a message of their extreme vulnerability and may become hesitant and cautious about normalization (Spinetta, et. al., 1976). At times, of course, parents and professionals may go too far in the opposite direction. By denying that problems exist, for the child or in the external situation, parents may fail to adequately protect their children. Indeed, it appears that at times children will need preparation and protection to face ignorance, cruelty or inflexibility on the parts of peers, neighbors or the school staff.

Reactions of peers and school officials

Peers, educators and other adults who play significant roles in the life of the child can have important impact in escalating or diminishing the impact of these potential problems. How these others react to the fact of childhood cancer, whether they are able to normalize their own relationships with the child and family, may make a major difference in how youngsters cope with these stresses. Several studies

stress the importance of others' reactions to the child as a major component of their adaptation to their illness and to future opportunities (Cyphert, 1973; Greene, 1975; Katz, 1980). Wortman & Dunkel-Schetter (1979) discuss the stereotypes and prejudices faced by adults with cancer, and our observations suggest children with cancer experience similar reactions. Peer teasing of an amputee, or of a child bald from chemotherapy, represent frequent worrisome problems during school re-entry (Katz, et.al., 1976; Moore & Triplett, 1980; Zwartjes, 1978). Peers may be worried about the disease's contagious effects, or uncertain about how to respond to what looks like a "special person." Teachers, too, may react stereotypically (Cyphert, 1973; Kaplan, et al., 1974) and isolate the ill child (Feldman, 1980), or even ridicule him/her. They may withdraw emotionally or ignore the child, perhaps out of fear or confusion about appropriate behavior. Some teachers, concerned about a child struggling with a potentially fatal illness, beset by emotional and physical drains on his/her energy, may inappropriately lower academic requirements (Katz, 1980).

Research Questions

On the basis of previous research, several questions emerge as relevant to our concerns about the problems involved in the school re-entry of children with cancer:

With respect to the child:

- What problems did the child experience upon return to school?
- What strategies were developed to deal with those problems?
- Did the diagnosis and experience of childhood cancer affect the child's school performance, self-concept, interpersonal relations, and life plans?
- Are there ongoing medical concerns which pose difficulties for the returning child?

With respect to the school staff:

- What problems did the school staff experience during the school re-entry of the child with cancer?
- How did the staff cope with those problems?
- How did they respond to the child's needs?
- How did the school staff resolve the dilemma of treating the child as independent and self-sufficient, without ignoring genuinely unique needs?

- How did the staff decide when they should reach out or let the student work things out on his/her own?
- How did the staff maintain standards, avoid patronizing and misplaced sympathy on the one hand, and demand no more than the child was capable of on the other hand?
- To what extent did the school and hospital staff share information and collaborate during school re-entry?

With respect to family-school relations:

- To what extent did teachers and parents develop open and continuing dialogue regarding the child?
- How did parents and teachers develop mutually trustful relationships through which to co-ordinate strategies for handling the child?
- To what extent and in what ways was the school staff helpful to the family?
- To what extent and in what ways was the family helpful to the school staff?

These questions provide a frame for our investigation. For some of these questions we were able to obtain only fragmentary or partial answers. In other cases we gained important insights about the school experiences of children with cancer and raised more questions to be answered in subsequent research and intervention projects.

Methods of Investigation

In order to bring to these questions an empirical approach that would advance our own and others' understanding, we generated several different data bases. First, some of the data examined in this study were gathered as part of a larger study of the stresses and coping patterns of families of children with cancer (Chesler, Barbarin, Chesler, Hughes & Lebo, 1981). In that study interviews were conducted with 55 families experiencing childhood cancer, including 94 parents (74 parents of children living with cancer and 20 parents of deceased children), 28 children with cancer and 21 of their siblings. Thirty-five of those families had living children with cancer of school-age at the time of the interview, and the data reported herein is limited to those families. This data set had two important limitations in terms of our purposes here: (1) all the data were collected from families being treated at a

single major university hospital (although they attended several different school systems), and; (2) the sample underrepresents non-white children and their families. Despite these limitations, a substantial amount of rich material regarding students' and parents' views of the school experiences of children with cancer was available from this data set.

Second, a small group of adolescents with cancer were involved in the school re-entry project as consultants. In that role they met with the project staff several times to discuss their experiences, and to consider, evaluate and comment upon the data from parents and youngsters (above). Throughout, these students reminded us of the special glasses adult researchers often wear, and the distortions or errors of omission and commission with which we, as well as other actors, operate.

Third, interviews were conducted with a total of 29 teachers, administrators and school counselors who had had direct experience with children with cancer in school. These educators were nominated by parents and students involved in the original study (Chesler, et.al., 1981) as having had direct contact with their children. During the months between the initial interviews with parents and the interviews with school personnel two children included in both studies died. Thus, although some educators did respond to the issues surrounding the death of a child in their class, this study primarily focuses on children living with cancer, and barely begins to explore aspects of the problem of death and the school.

Fourth, an additional component of the project was a conference for educators, held in the fall of 1981. The conference was conceived both as an information-collection and information-dissemination activity. With respect to information-dissemination, preliminary results from our study of the school experiences of children with cancer (the first three data bases above) were presented. In terms of information-collection, comments and discussion were invited from participants. Such

comments were useful in generating new insights, as well as in clarifying and correcting some interpretations of the data. Participants in the conference included 50 school administrators, teachers, and health personnel from school districts in Michigan and Ohio. In addition, a panel of adolescents with cancer, and a panel of parents of elementary school-aged children with cancer, made presentations. A fuller description of the conference and related materials are presented in Appendix A.

The information provided by parents and children in the original study, by the educators who worked with some of these children, by our adolescent and parent panelists, and by conference participants permit unique triangulations on the experiences of children with cancer in school. They provide some quantitative comparisons and a series of vignettes which capture portions of a very complex picture involving a wide variety of actors. The results of this pilot work are illustrative rather than definitive; however, they can serve as a useful base of information from which to develop further investigations or action-research projects. Moreover, some of the insights shared here may be of direct and immediate benefit to teachers, administrators, counselors and families of children with cancer. For each person (parent or educator), the experience with childhood cancer is often a singular long-term event. By providing a vehicle for sharing these experiences, this monograph may be a useful tool in helping families and school staff members anticipate problems and learn from others how to solve them.

This report is divided into four sections which cover the perspectives of: 1) parents; 2) school personnel; 3) adolescents; and 4) the medical staff. A conclusion and series of recommendations complete the report. In each of the following sections the relevant method and research data will be presented, as well as findings from other pertinent studies.

PART II. PARENTAL PERSPECTIVES ON THE SCHOOL EXPERIENCES
OF CHILDREN WITH CANCER

Substantial research demonstrates that active participation by parents in the education of their children can contribute significantly to interest and success in school (Keeves, 1975; Comer, 1982). When a child experiences a serious or life-threatening illness, this involvement may become a necessity. If a child is hospitalized for extended periods, the parent often is the primary link between the hospital, the child and the school. The parent can provide the school with medical information and guidance about what to expect once the child is ready to re-enter the classroom. The parent also may engender in the child a sense of belonging and continuity with classmates, by informing the child of school activities and events, and vice versa. In addition, the parent may act as negotiator with the school regarding assignments, requirements and timetables for completion of work. Once the child returns to school, the parent may be involved continually in encouraging the child to do academic work, in monitoring the child's physical condition and emotional adjustment, and in safeguarding the child against exposure to infections, diseases and inappropriate activities. These are important roles. If executed well they can make a difference in the ease with which the child with cancer re-enters and adjusts to school.

This section explores the school re-entry situations of children with cancer, as seen through the eyes of their parents. Responses to four different questions in the interviews with parents of children with cancer are presented and discussed.

1. To what extent were educators helpful to parents in dealing with re-entry?
2. What kinds of problems did parents observe with regard to the school's handling of re-entry?

3. What specific things did teachers do that were or were not helpful?
4. How did parents and their children adapt to the behavior and stance of the school staff?

As indicated on page 14, these questions were directed to a sample of 59 parents in 35 families with school-age children with cancer.

Were school people helpful?

Table 2 indicates parents' responses to the question of whether school people were helpful to them. According to their reports, in half the cases school people were quite helpful, but in the other half the school staff was described as not helpful, or only a little helpful. Table 2 also suggests that parents of secondary school age children (over 11 years) were somewhat more likely to report helpful responses from educators than were elementary school parents. Perhaps that is because these children and their parents had more experience with the school, and because these older children were more likely to assert themselves.

Table 2
Parents' Reports of the Helpfulness of
School People, by Various Demographic Categories

<u>Demographic Categories</u>	<u>School People's Helpfulness Very/Quite Helpful (N=29)</u>	<u>Little Helpful (N=24)</u>
By students' age		
11 and under (N=28)	47%	53%
Over 11(N=25)	64	36
By sex of parent reporting		
Mother(N=30)	57	43
Father(N=23)	52	48
By parents' level of education		
College graduate(N=17)	76	23
Some college(N=17)	34	64
High school or less(N=16)	38	62
NA (N=3)	100	0

In addition, more highly educated parents reported helpful responses from school people significantly more often than did parents with less educational background ($X^2 = 10.9$, $df = 2$, $p < .01$). Several different factors related to educators, the child and the parent may account for this finding. One explanation is that school people may have responded differently to parents with higher educational backgrounds, parents who were of the same or higher status as the educators. Second, perhaps the children of more highly educated parents were doing better in school to start with, and thus seen as "better bets" for educators to invest time and energy in. A third explanation is that parents with more educational experience themselves may have been prepared to be more assertive about asking for help for their children, or appreciated the help they did receive more than other parents did.

Helpfulness of school people may matter! Table 3 suggests that parents' experience of helpfulness may be related to their satisfaction with the school's response to their child. Although only 6 parents were not satisfied with the school's response, 5 of them also reported getting little help from the school. Moreover, parents who felt their child now was doing the same quality of work, or better, than before the illness, were slightly more likely to report school people as "very" or "quite" helpful. The numbers of children who were rated by their parents as doing less well now is quite small, too small for any coherent analysis of these issues, but the trend is clear nevertheless. The group doing better now than before also is too small for firm conclusions, but with a larger sample, Feldman (1980) reported that students with cancer from families with higher educational backgrounds were more likely than students from other families to improve their academic performance on re-entry to school. If higher educational background is related to parents' perception of more helpfulness from the school, and if more helpfulness is related to the child's

stable or even improved performance on re-entry, then this makes good sense.

Table 3

Parents' Reports of Helpfulness of School
People, Related to Other School Issues

	School Peoples' Helpfulness	
	<u>Very/Quite Helpful(N=29)</u>	<u>Little Helpful(N=24)</u>
Parental satisfaction with school's response to child:		
satisfied (N=37)	62%	38%
not satisfied (N=6)	17	83
NA (N=10)	50	50
Child's school performance:		
worse than before (N=4)	25	75
same as before (N=25)	64	36
better than before (N=5)	80	20
NA (N=19)	42	58
Child caught up and doing well in school:		
No (N=6)	34	66
Yes (N=41)	61	39
NA (N=6)	34	66

Children who were not doing well in school prior to their diagnosis sometimes had an especially difficult time catching up afterwards. In at least one case, a mother felt her son's problems in this regard were compounded by a lack of help from the school.

My son was different from some others because he was a "C" and "D" student before he got cancer. When he came home from the hospital no one called the house. All the initiative had to be ours, and we had enough to deal with already. I guess they figured that since he was not a good student to begin with, they should not bother. Besides, in their minds he was dying already. I think the school gave up on him, and as a result he gave up on school.

Many school personnel wondered how helpful they should try to be to the sick

child, and how much they should extend themselves to the family. Often reluctance to help was based on the fear that parents or colleagues would resent "meddling" or "overinvolvement." Because some teachers and school administrators were uncertain about how parents would react, they may have refrained from taking the initiative. Parents' reports suggest that these overtures of help may be welcomed, and highly related to parents' expressions of satisfaction with the school.

What kinds of problems did parents report?

We asked parents whether they and their children experienced any particular problems in returning to school. As Table 4 indicates, 30 of the 59 parents with school-age children, or 51%, reported problems. The two problems mentioned most often included missing much school and teasing or rejection by peers.

Table 4

School Problems Reported by Parents of
Children with Cancer

<u>Problems</u>	Number and Percent of Parents Reporting School Problems	
	<u>N=59</u>	<u>%*</u>
Mentioned any problem	30	51
Teasing by peers	22	37
Missed much school	18	31
Relations with teachers	7	12

*Since some parents mentioned more than one problem, the total percentage equals more than 100%.

Thirty-one percent of the parents reported that their child missed "much" schooling. The definition of "much" used here is at least a few days or more per month, over the course of years. Children who missed several days or even weeks at diagnosis

and the beginning of treatment, but who were able to attend school regularly after that, were not interpreted as missing much school.

Table 5 indicates that parents' reports that the child missed much school appear to be related to whether the child relapsed and the number of times the child was hospitalized. As we might expect, children who had relapsed more often missed "much" school than did children who stayed in remission (64% v. 26%), and children who had been hospitalized more than three (extended) times were more likely to have missed much school than those children who were hospitalized less often (58% v. 13%). Both these relationships are statistically significant (X^2 relapse v remission = 5.6, $df = 1$, $p. = < .05$; X^2 amount of hospitalization = 12.2, $df = 1$, $p. = < .01$). On the other hand, parents who reported that their children missed much school were no more likely than other parents to report that their children were not caught up with school, or that they experienced other problems, including teasing. Nor does there appear to be any relationship between the child missing much school and parents feeling they received different amounts of help from school people.

It seems clear from these data that while missing school may be a common experience for children with cancer, they do not all miss a lot of school; only a relatively small minority does so. Moreover, whatever the impact is of missing much school, it does not, in and of itself, lead to a host of other school problems.

Table 5

Relationships Between Parents' Reports that Child
Missed Much School and Other Issues

<u>Other Issues</u>	<u>Missed Much (N=18)</u>	<u>Did not Miss Much (N=36)</u>	<u>No Report (N=5)</u>
Situational Factors			
Has your child relapsed			
Yes (11)	64%	36%	0%
No (48)	23	67	10
How often has child been hospitalized			
1-3 times (N=31)	13	84	3
More than 4 times (26)	52	37	11
No answer (N=2)	0	0	100
How helpful were schoolpeople			
Very/quite helpful (N=29)	31	66	4
Little helpful (N=24)	38	58	4
No answer (N=6)	0	50	50
School problems			
Were there any special problems with the school			
Yes (N=30)	30	63	7
No (N=24)	29	63	8
No answer (N=5)	40	40	20
Was your child teased			
Yes (N=22)	32	68	0
No (N=37)	30	57	13
Is your child caught up with schoolwork			
Not caught up (N=6)	17	83	0
Caught up (N=43)	35	58	7
No answer (N=10)	20	60	20

The second problem many parents mentioned with regard to their child's schooling concerned teasing or rejection by peers. Over two thirds (22/30) of the parents reporting "particular problems" with the school indicated that teasing by peers had been a concern (see Table 4). Consider some of the following comments by parents:

There was some teasing. But he didn't want me to talk with the teacher or do anything about it. That would only make it worse, he thought.

Facing the kids when he first went bald was the hardest part. We taught him to laugh about it because that was about all he could do.

There was one turkey who really teased him a lot. He hit him and knocked out one of his teeth and that stopped it.

When there was a lot of teasing and fighting the teacher stepped in. Why didn't they do something before then?

Teasing is a typical event in the classroom, perhaps it even is normal. However, these children were inappropriate targets for such teasing, because of their obvious handicaps and their psychological vulnerability. Parents wrestled with what they and the school staff might have done or should have done to intervene in these situations.

In some cases peers' reactions went beyond teasing, to potential rejection of the child with cancer. As some parents commented:

She was treated like a leper.

The kids would make fun of him when he had no hair and when he was on medication and blew up like a balloon. There were remarks made to him that he was going to die.

In addition to concern about the reactions of other children, some parents were particularly troubled and angry at the reactions of other parents. Consider the following comments, and the potential relationship between these parents' actions and youngsters' teasing or other negative behaviors.

One mother told a neighbor that she didn't want her daughter hearing any more about my child's illness, because she was home crying since she heard about it.

The children were told about it in school, and they weren't too upset. But some parents were upset because their kids came home and they were concerned that their friend was really, really sick. Anyone would be upset. But the parents got mad that the school had said anything about it; they felt that the school shouldn't have told the kids and upset them.

I did have some parents call me and tell me that they did not want my child in school, because they did not want their children to come down with cancer.

Recent research on the psychosocial aspects of childhood cancer stresses that it is a family disease, in the sense that everyone in the family is likely to be affected by it. Moreover, of all family members, siblings often appear to be most "left out", to receive the least attention at home (Gogan et al., 1977; Sourkes, 1980; Spinetta, 1978). Some parents noted the problems this created at school, and were concerned about the school staff's sensitivity to siblings.

Her brother is often getting into fights because he can't stand the other kids teasing her. . .about her hair and everything.

The school let me down when they didn't understand my sick kid's older brother. I mean, a nice boy like that, who's never done anything wrong before, suddenly acting out. You'd think they would have anticipated some changes and been on the lookout, or at least been more sensitive when it happened.

The little one feels he isn't getting enough attention at home, and he's right. I need some extra help from the school on this one.

These reports suggest that problems in the school are centered not only in the child (e.g. missing school) but in the reactions of the child's teachers, peers, and parents of peers. Moreover the reactions of parents themselves, as well as siblings, must be taken into account. If all attempts to moderate the stress of school re-entry are directed toward the sick child, without attention to siblings and peers, significant sources of stress will remain unaffected and interventions will be incomplete and ineffective.

What did teachers do that was helpful or not helpful?

Faced with these children, and with some of the personal (physical and psychological), familial and peer problems reported here, what did or should teachers and other educators do? In Table 6 we report some things parents identified teachers

as doing that were helpful and some that were not.

Table 6
Parents' Reports of What the Teacher Did
That was Helpful or Not Helpful

<u>Teachers' Actions</u>	<u>% of Parents Reporting*</u> <u>Teachers' Actions</u>
Actions Which Were Helpful	
Was caring	39%
Treated child as normal	28
Gave special academic help	20
Kept parents informed	14
Actions Which Were Not Helpful	
Was insensitive	13
Was overprotective	10
Other	23
Nothing (everything was fine)	53

*Multiple responses cause the total percent to exceed 100%.

There appears to be a delicate tension or balance among some of these reported behaviors. If caring and giving special help is seen as positive, too much of it may be seen as overprotective. If treating the child as normal is positive, too much of that (in the face of non-normality) may be seen as insensitivity. Van Eys captured this dilemma in the following terms (1977, p. 168):

If the cancer were ignored by well-meaning people, the child's reality would be distorted and he would not be accepted as the person he is. On the other hand, when the cancer is made the overwhelming concern, the "normal" in the child that wants to be recognized is ignored. Either produces despair.

Let us consider some of these reported behaviors in more detail. Parents noted the following positive and caring behaviors:

She's just a super person. She gives him his medication and vitamins every day. If he's had a bad day (after chemo) she sends his homework home. She's very understanding.

I told his teacher that he had cancer and that if anyone sneezed on him he'd be sick. If a mother sent her child to school with a cold the teacher called me to take him home.

Two of the best teachers in Junior High have been super. They came to visit in the hospital, they saw to it that she had homework. They handled it beautifully by telling the children at school.

The kids sent cards and the school sent flowers and the teachers helped most. When he got back he was treated the way I liked.

They've done things that have made him more comfortable. Like they have a rule that you can't wear hats in school but when he lost his hair he could wear his hat. When he was tired, they had a rug in the back of the room in what they called the reading area, and as long as he was caught up and had his work done, he could go take a nap if he was exceptionally tired. At first he would do that quite often but he doesn't do that too much anymore. He's got more energy.

In addition to these examples of special caring, in and out of the classroom, parents also provided examples of the benefits of treating the child as normally as possible.

They just made her comfortable. They treated her like the rest of the kids with a few exceptions. That was real important to her.

They treated him like anyone else, or even a little rougher, which made him work a little harder. He plays hockey 3 times a week now.

They treated her normally, with no favors, which is what she and I wanted.

As Table 6 indicates, parents also reported a number of non-helpful or worse, negative, behaviors. Consider the following examples of insensitivity and an apparent lack of caring (for the child and the parent):

All were fine except for her gym teacher. I'm going to go in and rearrange his body. She had one kidney removed and I don't want her to do anything that might jeopardize her other kidney. I'm very touchy about contact sports. The gym teacher keeps forgetting her restrictions and lets her play tackle football.

During his therapy, one of the teachers told me he'd have to have a letter from a doctor at the hospital because he did not believe that he had leukemia. It must be all in my mind, he said!

One teacher didn't know she was on chemotherapy and that her memory was impaired. The teacher marked her down because she forgot to hand in some homework.

When present, the involvement and concern of the school staff can sustain student efforts; when absent, they can be a source of discouragement. As one parent

summarized her son's encounters with the school system:

He found out the teachers didn't care, so he lost interest.

When teachers do care, the ways in which they express their concerns, and the complex issues surrounding such expression, can effect whether the consequences are positive or negative. For instance, some negative consequences of well-meaning overconcern and overprotectiveness are captured in the following parents' report:

At first she babied him, was scared of him, and afraid to touch him. He was fragile to her. He sensed this and used this to his advantage.

In addition, inattention, lack of concern and thoughtlessness by individual teachers, the insensitive actions of administrators, and a rigid adherence to rules of the school bureaucracy also left parents confused and upset.

A year and a half ago I went over to school and asked about his credits and being able to graduate. They looked at the records and the counselor said he was fine and he'd be able to graduate with his class. Then he did well in school and all was forgotten until the 1st semester of the 12th grade. I received a letter stating he had no 9th grade English credit, and he'd have to go to night school to graduate. He enrolled in night school and attended. The more he thought about it, the more he said, "the hell with it, they lied to me, said I could graduate, and now they say I can't unless I do extra work." At that point, he dropped out of school. We went to the school for help and they denied it. It disgusts me. He worked his hind end off to maintain his grades and then they screw up down there.

The hospital sent the school a letter regarding his absences, and that he was in the hospital. Teachers called to offer assistance, but the principal gave them a lot of hassles regarding taking his final exams. He missed the last week of school, and the principal wanted him to take the tests right away. The principal didn't want the teachers to take them to the hospital and administer them either. Also, he was very sick and not up to taking them. The teachers tried to help him, but the principal was the problem.

Principal should have been better informed about help available to sick kids -- like a homebound teacher. We didn't find out about it for a while.

Even the best prepared and experienced teachers walked a thin line in deciding how to act, and in acting, in ways that were truly helpful to students and their families. Teachers new and inexperienced to these issues often responded in anxious and fearful ways, either ducking and ignoring issues or paying too much attention to

imagined difficulties and problems. These responses, while understandable, represent what many adults experience when facing and interacting with people with cancer. If teachers also were isolated from the family, unable to create or respond to effective mutual conversations about the child's condition and needs in school, their discomfort, and these problems, were likely to be exacerbated.

How did parents prepare their children to cope with these problems?

When children with cancer experienced problems in returning to school, they and their parents attempted to cope with these new threats and difficulties. One approach parents took was to support the child and try to help her/him ignore or ride through problems. As several parents noted:

I tell him, "Hang in there, it'll just be a while longer."

Basically I try and tell her that those kids just aren't cool. Don't pay any attention to them.

With the teasing we would just talk to him and smooth things over as best we could. We didn't get any help from the school officials.

Another approach was more externally directed, and involved parents in advocating for their child with the school or with other adults. Ranging from talking to pressuring, parents reported:

I talk to the teacher and get everything straightened out. Then she cracks down on the kids that tease him.

We went to the school board.

Before school started I went in and talked with the principal. I assumed he would talk with her teachers, but apparently he didn't. One teacher asked how long she'd be on the crutches, when her leg had been amputated. I called the principal and told him how mad I was. He said he thought word had filtered through!

One girl in particular continued to tease her after the others had stopped. Although she never wanted me to do anything about the teasing I called the other girl's mother and explained to her why my daughter wore a wig. The teasing stopped but we never told my daughter that I had spoken to the other girl's mother.

Both approaches may be effective, more or less so with different children and in different school situations. The latter approach, more externally directed, is more likely to open up (hopefully fruitful) exchange with the school staff. As such it is more likely to alter stressful school circumstances themselves. The former approach, directed at the internal emotional states and coping patterns of the child, is more likely to enable the child to buffer himself or herself against the full impact of school-related problems and stresses. These coping distinctions mirror the differences between what Lazarus (1981; Lazarus and Launier, 1978) has called stress-buffering patterns (wherein attempts are made to regulate internal emotional responses) and stress-reducing patterns (wherein attempts are made to alter external conditions creating stress). At this point in time, we have little evidence explaining why parents elect one strategy more than the other, and little data exploring the differential utility of these coping patterns. Similarly, although the school staff can support or encourage either parental approach, which they would prefer is unclear from our present data sets. Hopefully these issues can be explored in future research endeavors.

According to parents, some variations in the school experiences of their children are related directly to the intensity of the disease-treatment process and the course of illness. In addition, they report that the stance of helpfulness or indifference taken by the school staff does affect the quality of the child's school adjustment. A high degree of staff helpfulness is related to facilitation of the child's school re-entry and to parental satisfaction with the school. On the face of it, extending help to family and child seems to be such a natural, almost reflexive response to the situation of a chronic life threatening illness. Yet parental responses suggest that there are systematic variations in the teacher-related factors which contribute to variation in the classroom experiences and peer relations of children with cancer. In

the next section we present the school re-entry process as seen from the perspective of the school staff. Their reports can help us to understand more fully some of the behaviors and issues noted by parents.

PART III. THE SCHOOL STAFF'S PERSPECTIVES
ON CHILDREN WITH CANCER

This section presents the perceptions of school staff members regarding the school re-entry of children with cancer. Interviews with teachers, principals, school nurses and counselors sought four major classes of information:

1. What problems occurred with chronically ill children in school? To what extent were regular school attendance and expected rates of school achievement disrupted by clinic visits and hospitalization? What was the quality of the child's emotional adjustment upon return to school?
2. How did the school try to help children with special needs? What accommodations, if any, did the school make to smooth the child's re-entry and increase the likelihood of successful school adjustment? Did these accommodations occur at an individual level, as a consequence of the personal efforts of a single teacher within a single class, or did they occur as a result of system-level programs or changes in the school? Was the assistance provided by the school staff related primarily to school achievement, or did it extend beyond professional tasks to include emotional support, practical assistance, mobilizing neighborhood and community resources, etc.?
3. What were the school staff's own experiences and reactions to the child's illness? What stresses did teachers personally encounter with seriously ill children in school? How did they cope with these stresses?
4. What help did the staff receive in dealing with these problems? What help might they find useful in dealing with such issues in the future?

In order to pursue these questions, we used an open-ended interview and a structured questionnaire to frame conversations with twenty-nine teachers, administrators and school health professionals who had had experiences with children with cancer in school. In all cases, the child and parent had participated in the larger study (Chesler, et. al., 1981), and had given permission to contact their current and past educators. Educators interviewed were distributed among elementary, junior high and high school; different ones had had contact with children with cancer at various stages of their illness -- at diagnosis, during remission or just prior to the

child's death. All educators we contacted agreed to an interview, and many expressed great interest in talking further with others who taught children with cancer.

Problems Faced by Children

Table 7 presents the proportions of school staff members who reported that the child they taught experienced problems of the sort included on the questionnaire. Inspection of this table shows that the problems mentioned by the largest proportion of educators were teasing from classmates, physical discomfort from medication or surgery, low academic achievement and difficulties in peer relationships. None reported a high degree of concern about issues such as excessive parental demands or lack of trust between the family and the school.

Table 7

Proportion of School Staff Reporting
School-Related Problems of the Child

<u>Child's Problems (N=23)</u>	<u>Somewhat Serious Problem</u>	<u>Slight Problem</u>	<u>No Problem</u>
Teasing from Classmates	44%	11%	44%
Discomfort from medication/surgery	43	13	43
Low academic achievement	32	18	50
Difficulty in relationships with peers	28	32	50
Frequent absences from school	9	56	35
School Phobia	5	0	95
Taking physical risks	5	36	59
Emotional adjustment	4	39	57
Lack of Parental trust in school staff	0	27	73
Parental demand for special attention	0	27	73

School Absence. Because of the frequency and duration of medical treatment for cancer, frequent absences was expected to pose a serious and universal problem for children re-entering school. We did not find this to be true for this sample: only 9% of the educators we interviewed reported that frequent absence from school was a somewhat serious problem. This is not to say that absence did not occur, but that absence itself did not create serious problems for many youngsters. Consider the following comments by educators:

She would be absent a couple of days for treatments and there was another period of about a week when they either changed medicines or something. But she made up work and kept going right along in pretty good shape. She is in the third grade now, has not missed a grade and will continue to progress.

He was absent about average--other children had worse attendance records. He was able to return and was very able to join right in and pick up what he

missed--I never had to send work home.

She was not absent a lot in my room but once she was exposed to mumps and had to be isolated for two weeks. She wasn't hospitalized at all that year. For treatments she'd go for a day, every other Friday. Even though it took a lot out of her, they could usually be back here by 3 p.m. and she would always want to come into the room. As the year went on, they cut down on her therapy. It was a problem in one way because she was gone on a day when we often had parties. Missing school activities and parties because of treatment was hard for her to handle but she took it in stride.

These reports become even more credible when we consider that parents (in the prior section) also stated that school attendance was not a major issue.

In the case of a relapse, of course, unexpected and more severe treatments and hospitalization may occur. At this point, despite the motivation and wishes of the child and family, absence may become a very serious problem which disrupts educational progress.

He was not absent much initially, but at the end of the school year he was absent a great deal because he had another relapse. But he was an outstanding student. He loved to read and the homebound teacher would come to the school and pick up library books for him and she worked pretty close with him. I always tried to let the homebound teacher know that he was in great shape but I knew that he always wanted to get his work done and that the absences bothered him a great deal. He had this great concern that when he came back to school, the other kids would know more than he did.

Teasing. Teasing from school-mates emerged as the most common serious problem reported by children with cancer and their parents (see prior and following sections). In this sample of educators, almost half rated teasing as a somewhat serious problem, and 28% reported other problems in peer relationships. Often teasing came from students in other classes, since teachers usually dealt preventively with teasing problems when the ill child was in their own class. In one case, however, the problem got so bad that the mother went to the teacher because the child complained that he was being teased about his hair loss. As the teacher reported:

We (principal, teacher and parents) made arrangements for him to leave a little early one day and I talked to the rest of the class about it. Of course some of the children knew that he had been sick because some of them had been in class with him the previous year, but a lot didn't know. I just said that he was sick and that he had a blood disease. They were very concerned about things

like whether they could catch it, why does the medicine make his hair fall out. Some of them became very indignant that anyone would tease him about it. A couple of the boys said if they heard anyone poking fun at him, they were going to belt them. I told that if they heard anyone teasing (him) they should just stand up for him and tell the other kids to lay off and explain that it was the medicine that made his hair fall out. They were very quiet. Later in the year I got up at a staff meeting and talked about it to make the other teachers aware that there was a student in the school who had a hair loss and the reasons for it, and that gave them an opportunity to talk to their own students about it.

The staff's direct and sensitive handling of a problem such as teasing can be very effective in defusing a volatile situation. In more general educational terms, it can help other children grow in their ability to empathize with and care for their peers.

Other Problems. In some instances, problems arose about which the school staff could do little except exhibit patience and understanding. One example was the physical discomfort children sometimes experienced as a result of treatment: 43% of the school staff indicated that the child's pain or physical discomfort was a somewhat serious problem. As one teacher remarked about a first grader with leukemia:

She lost some hair and some weight. She was a little pale and tired a little more easily. She is an average child with lots of grit and guts and I'm sure she was in school some days when she didn't feel great.

Similar experiences were shared by other educators:

She was sometimes very, very pale--almost white. She was often very immature after treatment--almost babylike. I think she hurt and that's when her mother let her bring stuffed animals into class a lot as a sort of security. I noticed this sort of clinging to something she loved. I think that was very necessary to her at the time.

The gym teacher noticed his inability to keep up--he could barely run. That in turn affected recess times. When everyone would go out and play, he would just walk around by himself

In spite of the many discomforts attending the illness and its treatment, staff members felt these children were willing and often eager to return to school. Ninety-five percent of the educator sample reported perceiving no difficulty regarding school phobia or persistent uneasiness or fear of returning to school. Consequently the rate of school phobia in this sample of children with cancer is not noticeable.

However, earlier investigators (Lansky, et al., 1975; Futterman & Hoffman, 1970) observed higher rates and expressed a greater concern for school phobia in their studies. Futterman & Hoffman (1970) report on a single case, and Lansky et al. (1975) observed school phobic reactions in 11 children. The hospital at which the latter study was conducted had an active case load of about 100 children. If all of these children were of school age (which is not likely), then the rate of school phobia would be at least 11%. Since neither of these two studies intended to estimate the incidence or prevalence of school phobia, the discrepancy between our findings and their reports may be more apparent than real.

Anecdotal reports suggest that when the school staff's relationship with parents was satisfactory prior to the child's illness, the child's re-entry to school increased staff-parent contact and strengthened the relationship. When the previous relationship was neutral, by virtue of minimal contact between staff and parents, the illness often increased the amount and intensity of contact. As a consequence of the new tasks and problems involved, re-entry sometimes resulted in a redefinition of the entire family-school relationship.

The Helping Process

Although some of the problems noted in Table 7 appear often and are serious, and others not, they all indicate some need for continuing attention and care. Staff members tried to help solve the problems of these children and their families in a variety of ways. Who and how did they try to help?

Recipients of help. To whom did the staff provide help? Often, staff members found themselves in a position to provide help not only to the child, but also to parents, siblings, classmates, and occasionally other school staff members. Table 8 indicates that the child and the child's mother were given help by the largest proportion of educator informants: 80% of the school staff reporting providing

assistance to these persons. On the other hand, less than half of these educators reported providing assistance to the siblings, and many observers confirm that siblings of children with cancer often were ignored during the early stages of the illness (Kellerman, 1980; Spinetta, 1978). At least one teacher and family dealt with potential sibling problems directly, according to the teacher's report:

The first conversation was on the telephone with the mother and we had subsequent meetings centering primarily on the effect on the sick child's brother. We started by getting him involved in the cross-country program here - he was a good runner anyway. We wanted to make sure that his needs were also being met. The mother was very realistic about the situation and her approach was that if there was one casualty in the family she didn't want two.

Types of help provided. In addition to providing help to the child with cancer in the classroom, some teachers reported reaching out to the ill child at home or in the hospital. Such help was often of an emotional and socially supportive character. Sometimes, it occurred on a one-to-one basis, and at other times teachers organized other people to provide support. Consider the following two examples:

I went over to her house when she was isolated. I took her some papers and talked to her. She was getting quite lonesome for her friends and her mother said it was a very hard two weeks for her.

The school sent flowers right away. We spent a lot of time talking with the kids about whether they would be going to the funeral and whether they had ever been to one before. I felt very good that on the day of the funeral many of the children in my class went and some of them also went to visit at the funeral home. A lot of the teachers from the school, as well as the principal and the secretary, went. The school also collected money for a memorial fund and got people involved in helping to make food for the funeral and the brunch to follow. The teachers brought dishes and the cooks prepared things as well. There was a lot of involvement that way.

Table 8 indicates the range of help educators reported they provided to various family members and other people dealing with children with cancer.

Table 8
 Help Provided by School Staff,
 by Recipient and Type

<u>Recipient of Help</u>	<u>Proportion of School Staff Reporting Providing this Help (N=29, 100%)</u>
Child	80.9%
Mother	80.9
Father	61.9
Other school staff	61.9
Classmates	52.4
Siblings	47.6
 <u>Type of Help Provided</u>	
Emotional comfort or support	76.2%
Listening to parents' problems	47.6
Holding parent or child	42.9
Taking assignments to hospital	38.1
Extra academic assistance to child	38.1
Crying together with parents	33.3
Solving problems of child discipline	33.3
Playing with ill child	33.3
Looking up information	28.6
Visiting child in hospital	14.3
Asking doctor for information	14.3
Raising money	4.8
Taking parents out to enjoy themselves	0

Although considerable variety is evident in this table, three-fourths of the educators reported they provided emotional comfort and support, and substantial proportions reported closely related actions of listening to parents' problems and holding them or crying together. The types of help provided least frequently were: 1) asking doctors for information, 2) visiting the child in the hospital, 3) raising money for the family, and 4) taking the parents out. With the notable exceptions of providing emotional support, holding parent or child, and crying together with parents, most of the common helpful behaviors were in keeping with educators' professional roles. Listening to parents' problems, taking assignments to the hospital, providing extra academic assistance, solving discipline problems, etc., all are within the traditional definition of teachers' roles.

Dilemmas of Help-Giving. The problem of role definition was an almost universal source of stress for staff members who wished or tried to be helpful. Having a seriously ill child in class was a new situation for which their traditional relationships with children and families seemed inappropriate. They had no model to follow, no clear guidelines by which to distinguish helpfulness from interference or intrusion. They were concerned about being active, also with not being too active. To resolve this dilemma, teachers and administrators had to rely on cues from the family to judge when their interventions were wanted or unwanted. In the absence of information or feedback from families which established clear boundaries, educators sometimes experienced role ambiguity. They often were uncertain about whether they should maintain their professional "distance", or whether they should act as a "friend".

Although responses to this dilemma varied considerably, the cases in which re-entry was handled most smoothly almost always were characterized by educators as times when school personnel went beyond the normal boundaries of their roles as professionals. Less successful transitions were reported when school staff members

were unable to resolve the dilemma regarding their professional role in a way that resulted in a new role definition.

I just always wished that I could have done more. I felt helpless at times about the teasing and about the problems he had in running and other physical activities but I didn't really feel that there was anything I could do. I didn't feel very involved and I wanted to be more involved. He never confided or shared his feelings with me, but now and then I wonder if I had let him get away with something that others didn't.

I really feel that I should have visited her in the hospital, which I did not do. My experience of 34 years in a school system is that regardless of how sick a child is, they really enjoy contact with their teachers or principal and cards from the kids. Why I didn't go, I really don't know, but it wasn't the easiest year for me.

Some staff members felt insecure and worried excessively about saying the wrong thing to the child. Some consciously withdrew, and intentionally limited their involvement to avoid censure or criticism from colleagues or from parents regarding how they handled the child. Others just felt it was too painful to get too close. Those professionals who defined their roles narrowly often felt they were unable to be as helpful as they might have been or wished to be. This dilemma is not unlike what close friends faced as they decided whether to take a risk by seizing the initiative, whether to reach out and help without being asked (Chesler, et al., 1981). Signs from parents about how close and accessible they want to be are subtle and difficult to read. When parents do not confide in the staff, or do not indicate directly that they are receptive to and appreciative of help, school staff members face a difficult choice.

The Staff: Personal Problems and Coping Patterns.

Research on school re-entry of children with cancer largely has overlooked the personal emotional issues which confront teachers and administrators of seriously ill children (Greene, 1975; Cyphert, 1973). Understandably, most research has attended to the problems of children and their families. Since the school staff can play a

crucial role in the child's adjustment and success, it is important to understand the issues these people face when children with cancer return to school. Thus, we asked staff members to discuss their own experiences, the stresses they encountered, and the ways in which they coped with stress. This approach reflects our conviction that childhood cancer is a shared experience. Educators, like parents, the family's friends and the child's playmates, are affected by the child's impaired health status, by the possibility that the child may die prematurely, and by the struggles brought about by living with a serious chronic illness.

Table 9 presents staff members' responses to queries about the personal stresses they experienced in dealing with children with cancer. Among the most frequently mentioned serious problems were a lack of specific details about the child's health status (60%), and a lack of knowledge about the disease itself (43%). Lack of information increased the stress of the child's school re-entry for staff members because they did not know what to expect, and had few guidelines by which to direct their own behavior. In this regard, lack of knowledge probably helped create two other problems mentioned often as serious: uncertainty about how demanding to be (50%), and uncertainty about how to discipline the child (50%).

Personal reactions. Some educators also reported strong personal reactions, such as concern about death and dying, and feelings of pity for the child and parents. These reactions often were intense and traumatic, marked by a combination of sadness, fear, and anger--many of the same feelings that parents experienced upon learning about the diagnosis.

I was surprised because he seemed like such an average, normal student and he didn't have any real personal problems. No one ever said anything to me about it. You begin to see the vulnerability of everyone. It seems to be happening more and more and it comes closer to you. You can't assume that it is on the other side of the fence--you have to deal with the situation. With any disabled student, it makes you aware that this is a reality of life and there for the grace of God, go I.

I really felt bad--like it wasn't fair. The usual reaction that someone so young is not going to grow up. He was a very responsible little boy. I guess the greatest thing was that my emotions would come in--feeling sorry for him and pity. I guess I was having a hard time dealing with the emotions.

Table 9

Proportion of School Staff
Reporting Personal Stresses or Problems
(N=29)

<u>Personal Stresses or Problems</u>	<u>Serious Problem</u>	<u>Slight Problem</u>	<u>No Problem</u>
Lack of specific details about child's health status(N=25)	60%	12%	28%
Uncertainty about how to discipline the sick child(N=18)	50	6	44
Uncertainty about how demanding to be of the sick child(N=18)	50	11	39
Lack of general knowledge about cancer(N=21)	43	24	33
Personal concern about death/dying (N=24)	16	46	38
Tendency to pity(N=21)	10	38	52
Absence of support from other teachers/principal(N=23)	0	39	61

Intense emotional reactions to the diagnosis sometimes were exacerbated and intensified by staff members' identification with the particular child or family. Several teachers who had children of their own of the same age spoke about it as follows:

Because I'm a mother, too, I think I felt very keenly what they were going through. And yes, it made me feel differently towards them. I knew the heartache they must have been going through and could also recognize the courage with which they handled it. I felt it keenly inside, but tried not to treat her differently.

I internalized it in terms of my own family, and I knew the other two kids in the family, so I wondered how the family would weather the storm.

I listened carefully to all the optimistic comments and I wanted to believe them. I did and so the stress level (though there was some) was never great. It was a defense mechanism because I don't like to face these problems myself.

Teachers who experienced a combination of pity and sadness for the child often reported ambivalence about dealing with academic demands and behavioral controls.

I was worried because I wanted to do the right things for him without overdoing it or underdoing it. He was so young and such a beautiful little boy. It's hard to separate your feelings and emotions so he isn't spoiled or smothered. We had to be very consistent and he had to be treated like the other kids. Even if you wanted to give in to him, you just couldn't do it. I felt that they would help him the best.

For some, ambivalence occurred after the fact:

I would have given him more slack, if I knew (about his illness) when I taught him.

Fifty percent of the staff members interviewed expressed difficulty around deciding how demanding to be of the sick child and how to discipline the child. Although many sought to maintain academic and behavioral standards, they were uncertain about what they reasonably could expect of the child. Many vaguely suspected that medication might increase fatigue and irritability, and reduce the child's ability to concentrate, but they were not certain. They wanted the child to keep up, to attain prior academic goals, but if the child failed to do so they were uncertain whether to attribute it to the child's motivation and effort or to the child's physical condition.

Decisions about issues of academic standards and behavior became more difficult when teachers feared recrimination, criticism or "second guessing" by their peers, by administrators or by parents. On some occasions, teachers reported that others told them they felt they had overreacted or underreacted.

Her mother felt that a few times when she had called home because she wasn't feeling well that she should have stayed in school. After that I was a little more cautious about sending her to the office when she didn't feel well. I may tend to be a little overprotective at times with kids who have special problems. Maybe "overprotective" isn't the right word--rather "aware", "concerned".

Some other issues of this sort are reflected in Figure 2.

Figure 2

Issues/Concerns Teachers Reported in Responding
to Children with Cancer in School

- Fear of having to tell my students of her death
- Constant worry about child's getting hurt; responsibility for physical well-being of children in physical education class
- Lack of information about what teacher in hospital school was doing; inability to coordinate activities
- Other teachers' intolerance of or insensitivity to the physical limitations of child with illness
- Criticism by parents for being over-protective of the child, e.g., letting her go home prematurely when she said she's not feeling well
- Lack of communication from parents about child's status
- Lack of certainty about what to do about specific problems, e.g., nausea
- Inflexibility of school and principal with respect to handling children.

The uncertainties involved in handling any seriously ill child are exacerbated by most staff members' lack of experience, knowledge and skill on these issues. Few educators have received formal training or education regarding students with serious illnesses. Several described their need for better preparation and training in the following terms:

I need more awareness training and information about what to expect during special illnesses and disabilities. How should I deal with the expected and unexpected things that happen?

It would be especially helpful for principals to get information about how to deal with teasing and how to communicate with families which are not really as open as this one. Then they could be available for teachers and arrange for their staff to receive some sort of training.

At the same time, however, others expressed ambivalence about the effectiveness of any general training program.

Every teacher is different and the training they would have to get would have

to be individualized. I don't know whether you can train people to handle this and I don't think more knowledge of cancer would have helped me one bit.

In-service workshops and training sessions might be helpful, but I don't think most school personnel would be interested, mainly because of our own fears about it.

Many of the problems faced by school staff members are much too complex to be solved by a brief in-service training program. Although training may be useful for filling specific information gaps and for learning strategies to handle recurrent problems, children, families and schools vary so greatly that simple prescriptions fall far short of what is needed. Instead, it may be helpful to view this problem within a broader context, one which goes beyond the provision of information about the disease and treatment to include a full variety of interpersonal and interactional issues. Educators repeatedly report personal and professional anxieties about doing the wrong thing, about managing peer relations in the classroom, and about maintaining liaison with the family. The systemic aspects of these issues must be dealt with, and attention paid to solving problems in collegial relations, support of the family, administrative responsiveness to atypical children, availability of pertinent instructional resources, and linkage to other community services and agencies. If these issues are to be handled adequately, a new view of the school's role must be fashioned -- one that involves a closer partnership among home, school and medical care organizations.

Coping. What strategies did school staff members utilize in order to cope with the multiple problems and stresses they faced? The most common response by educators centered on attempts to maintain normalcy. This response falls somewhere between a goal and a prescription for action. Some teachers described it as follows:

I checked his academic standing during the first several marking periods and there was no problem. If he had started to have problems, the flashing light would have started and we would have gotten everyone involved. But we didn't want the counselor or anyone else to stigmatize the kid so the information about the illness was not shared. He wants to be normal, like the other kids,

so we kept it kind of low. Possibly I should have called him in and told him I knew he had cancer and wished him well and talked with him about it pretty directly, but I chose not to do that and now I think it was wise. This is an unusual situation where there is a young person with a very serious illness which is arrested and he can lead a normal life.

It is important to treat the child normally and not to give her special favors. Her health was much more important than the school work and we did not want to put pressure on her to catch up. We had talked about the fact that if there were excessive absences (which did not materialize) that she might have to be kept back one year and her parents agreed, but this did not happen. We did a good job by basically doing nothing.

I think it is so very important that we treat them like everyone else. We want to protect them and the reason I didn't overprotect was the admonition from her parents to not do it. They need to feel normal, like they are part of the class, like the rest of the kids. I found her a very normal child other than the fact that she has to be protected from infections. I didn't agree with some of the things her two previous teachers did (they treated her with favoritism, special attention, prayers).

Appropriately, this goal also is a common recommendation of special education experts who write about children with cancer: "Each child must be treated according to his individual and specific needs. Above all other considerations, the child with cancer must be made to feel as 'normal' as possible (Kirten & Liverman, 1977, p. 170)."

Other responses teachers made to this question are presented in Figure 3. These strategies deal almost exclusively with the instrumental problems teachers faced, such as absence, physical impairment and irritability, and concern on the part of the child's peers. In general, teachers seldom reported what Lazarus & Launier (1978) have described as emotion-focused strategies, strategies designed to regulate affective reactions to stressful situations. Educators' failure to describe how they dealt with their own feelings about the child with cancer in school may be seen by some as a prime example of a professional attitude, and of the ability (or disability) to gain distance from one's strong feelings. On the other hand, this response trend also may be an artifact of a narrowly constructed interview question, rather than a real indication that educators do not have, or do not acknowledge, such feelings. As

we have noted, many teachers did describe the very strong and distressed reactions they experienced in thinking about children's chances for survival, as well as their struggle for normality.

Figure 3

Instrumental Coping Strategies Employed by Teachers

When she was absent from school social events I would save her a treat.

Ignore immature behavior, treat her like other kids.

When she had to be isolated from other classmates, I would go to her home, take papers, and talk to her

Seat student with sight/hearing problems in front of room

Prepare other kids for his return by talking about it ahead of time

Treat child normally, like a normal person; give extra concern, reassurance but not extra privileges, coddling

Reassure (child) that he can have the time he needs to get assignments done

Use regular Parent Conference, call at home to find out about child's status

Talk with Public Health nurse and clip magazine articles to obtain more information about the child's illness

Deal with anxieties of other parents

Talk to colleagues who are insensitive

A glimpse into the personal and emotional impact of working with children with cancer is provided by examining educators' responses to questions about the ways in which they changed as a result of their relationships with these children and families. The data in Table 10 suggest that a significant proportion of the school staff was forced to grapple with the meaning of life and death, and to place many issues in a new perspective. For example, school staff members reported a marked increase in

patience (60%), faith in God (57%), sympathy for the sick (54%), and understanding of death (54%). Like parents and friends of the family, educators working with children with cancer re-examined attitudes and values which, in the normal course of life events, go unchallenged. For some, religious faith provided comfort and gave meaning to the suffering of innocents. For others, minor life irritations were dealt with more patiently when weighed against the grave inconveniences they saw children suffer. At some level, indeed a level we did not examine explicitly, this experience may have affected how educators and others now appraise and cope with many of their own life problems.

Table 10

Proportion of Teachers Reporting Areas of Their Lives Changed by Their Experiences with a Child with Cancer

<u>Life Changes</u>	<u>Much More</u>	<u>More</u>	<u>About the Same</u>	<u>Less</u>	<u>Much Less</u>
Being patient with minor problems (N=25)	60%	8%	24%	4%	4%
Faith in God (N=23)	57	13	22	4	4
Sympathy for the sick (N=24)	54	21	13	4	8
Understanding of death (N=22)	54	18	18	0	9
Desire to help others (N=23)	52	26	13	0	9
Anger towards the medical system (N=18)	50	28	22	0	0
Willingness to get psychological help (N=24)	50	0	42	0	8

Educators' ability to handle the specific tasks presented when the child with cancer re-enters school appears to be mediated by personal, situational and organizational variables. Personal variables include the intensity of the staff member's emotional reactions and the amount of experience the educator has in dealing with seriously ill children. Several teachers with previous experience seemed to feel greater comfort and confidence than inexperienced teachers in handling problems which arose.

Having experienced it (the death of a child in my class), I still wouldn't want to experience it again, although I feel that I am much better prepared to face it again if I have to. It's so painful to see a child go through this. I was very fearful when I first found out about it, very anxious. But now, looking back, I am very glad that I was his teacher, that I had the chance to know him and that I developed the relationship I have with his family. The experience has led to a great deal of new types of learning around the whole issue of death. I have done some activities this year that I wouldn't have done without having had this experience. It has made a difference in my teaching and I feel that now I will always incorporate it, even though hopefully I won't have to experience that with a child again.

Situational variables also affect the educators' responses. One example of a situational variable is the degree of the child's maturity. Several staff members reflected on how much of a difference the maturity of the child made in helping them to cope with the situation.

He seemed to be a very mature-thinking little boy. His parents were very straight with him. He was a real deep-thinking mature kid. He was the oldest in the family, too, which may have made him more serious.

They have more of a tendency to want to do something and follow through on it and finishing it. Sometimes I think when someone has something like cancer, they have a stronger feeling about life in general, maybe because it's pretty precious to them.

I always felt that he tried to remain somewhat aloof and purposefully tried not to become attached. I don't know if it was a planned thing but I wondered if it was a conscious attempt not to become overly close to people or to form strong attachments. Perhaps he realized so much more than people think he did. He was very sensitive and it would often show up in his writing. He wrote some very beautiful poetry and would make connections with things that other children would not make.

Another situational variable is the role parents play in the school re-entry of the child with cancer. Clearly, parental behavior affects the ability of the school staff to cope with their own stresses, as well as with classroom problems. Several staff members noted parent's impact on the child's behavior or outlook, and on the degree of information and feedback they provided to teachers.

The success of the situation was due primarily to the way he was brought up. We only have him here six hours a day and the support he gets from home is the primary reason. I could call the home and they felt very comfortable calling here. Some of the family things we talked about were probably things a counselor should have been involved in. The mother was very open and we not only knew about problems as they occurred but also developed empathy about what problems might arise.

The parents came in to talk to me several times and I brought up the topic with them also. The closeness between the parents and the school and the whole atmosphere made her a good normal person. I maintained steady contact with the parents and they told me whenever her medicines were changed and if she had had a bad or good day or night. What the parents did was wonderful--they told me everything that was happening and there was close communication between the home and the school.

When I asked for information, I got it. I made contact with the mother before a scheduled conference, because I wanted to know of any limitations, or symptoms. If he were to have problems in the class room I wanted to know how to handle it. She was always trying to treat him as normal so the initiative always came from me. It is important for parents when dealing with the school to be open, to have a free-flowing communication, to trust each other, to be specific about what they want and to be willing to answer questions and give all the background information possible.

Organizational influences on educators include the general climate of the school, its degree of personal concern and warmth, and the leadership provided by the school's administration. Factors which influence the climate of the school also are likely to effect the way everyone involved copes with childhood cancer. In addition, structural factors, such as whether the school is elementary, intermediate or secondary may play a role. In the next section the role of organizational influences is discussed in greater detail.

Help for the school staff

As some of the above comments suggest, some educators felt they received considerable help and support from others. Table 11 indicates that the largest proportions of educators reported receiving support from the child's family (90.5%) and the child (71.4%). A little more than half of the educators reported getting support from the principal and from their peers.

The greatest help you get is from other teachers or the principal. The social workers just can't feel the impact of it like another teacher who's there every day. The social workers deal in isolated situations and they feel it differently.

When peer support was available it seemed to be extremely important in helping teachers gain perspective and balance in dealing with these issues. One teacher, whose student with cancer died during the year, commented on the importance of the help and consolation provided by her professional peers.

The support of the other teachers meant a great deal to me. I came back to school very late on the day of the funeral to return some pans, and people were surprised to see me. His previous teacher came over to me and said something to me and I started crying all over again. The principal also came over. Two of the middle-aged teachers said that it must have been a very hard day for

me, and that never in their years of teaching had they experienced the death of a student, and that people can teach for years and years and never have that experience. People came up to me and were very understanding.

However, this experience of peer and administrative support was not universal. In some cases, teachers found very little support from the principal or other teachers.

The principal would have gone to pieces and been so upset that he would not have been able to give me any special help. I would not have gone to either of the two previous teachers she had previously because I did not agree with some of the things they did.

Table 11 indicates that only 1 educator (4.8%) reported receiving help from the medical staff. This is not a surprising finding; since the local hospital and medical center had no systematic outreach program for schools their young patients attend, any direct or indirect contact with the medical staff would have been rare.

Table 11 also indicates the types of help educators received. As many of the prior quotes indicate, information about the child's medical situation was very important, as were specific suggestions for classroom activities. Emotional support also was reported by more than half of the sample. Some educators experienced many different kinds of help from many different sources; they were extremely fortunate.

Table 11

Sources and Types of Help Reported by Educators

<u>Source of Help</u>	<u>Proportion (N=29)</u>
Child's Family	90.5%
Child	71.4
Other Teacher	57.1
Principal	53.6
Nurse	42.0
Own Family	38.1
School Counselor/Social Worker	25.0
Physician	4.8
<u>Type of Help</u>	
Information about child's health status	90.5%
Information about effects of treatment	85.6
Guidance about what to expect of child	76.2
Tips on behavior management	61.9
Emotional support	61.9

Table 11 presents a dilemma which requires addressing. Earlier, educators described the lack of information about the child's situation as a significant problem. At the same time, data in table 11 suggest that a substantial number of informants received information about the child's medical condition. While it is true that many educators were provided with information, their information needs were not always met with respect to timing, continuity, quality and depth. Teachers often described

information problems in terms of a lack of direct contact with parents. Indirect information, coming from the ill child or other students, was not necessarily convincing as to accuracy. In other cases, if the information had been provided earlier, the teacher could have used it to anticipate and prevent school problems. In still other cases, the school staff did not get the type of information that they needed. They received facts about the child's illness, but not interpretive information that would help them use facts in ways that could direct their behavior toward the child. Thus, it appears that the information the school staff felt it needed regarding the medical situation are parallel to that of parents who sought information about their child's health. In both cases, the concrete medical facts were not sufficient.

The following excerpt provides a graphic vignette of a mutually helpful relationship among family, classmates and school staff. It is an excellent illustration of how cooperation, caring, open sharing of information and breaking of artificial boundaries can make a difference in helping each of the individual actors make it through a difficult period.

The previous teachers had told me that the mother had been in very close contact with them and sure enough, within the first two days of school she called and wanted to know if she could come in and sit down and talk with me about it. And she did within three days. She said that if at all possible he would be in school because he really liked it and he didn't particularly like going in for treatments. She gave me a booklet for the teacher of a child with cancer and she invited me to attend a lecture on the topic with her. That happened to be a night that I was attending a class so I couldn't go. She gave me a lot of information about his exact case and said that if I had any questions she would be happy to help me with anything she could. Shortly after that she saw me again and wanted me to talk to my class because he said that he had frequently been teased about his hair loss. We discussed the way that he wanted me to tell the class.

When the mother first talked to me and gave me all kinds of details, I wondered to myself how she could be so matter of fact and thought it was probably because she had done this so many times with so many people. I was somewhat amazed by her openness. I questioned her about how he felt about all of this and I wanted to know if he would ever talk about it or share it with me or with the other students or if he would write about it. She told me some of the things that he told the family at that time but not much. I thought she was an incredibly strong person.

After he became terminally ill and I started visiting their home and I saw the kind of strength in that home. When I visited there, they gave me the strength that I needed because I didn't know how I would get through that visit when I laid eyes on him. I was ready to just leave the room because it really bothered me and I didn't know what to say or what to do but his family made it easy for me. They were so uplifting. And after that, I visited him on a number of occasions and I got to know them so much better. Since then they have become very close friends of mine.

Our task, obviously, is to encourage the creation of just these relationships. In so doing, the quality of life of everyone involved is improved -- especially that of the child with cancer.

PART IV: ADOLESCENTS' PERSPECTIVES ON SCHOOL RE-ENTRY

Certainly children's lives are disrupted by the experience of cancer. But in what ways, to what extent, and with what effects? How well founded are concerns expressed by Weinberg (1970) and Stubblefield (1974), that serious illness, and its treatment, necessarily impedes academic achievement and arrests emotional and psychosocial development? Does the experience of cancer necessarily impair children's self-concepts and disrupt relationships with school peers (Bakwin & Bakwin, 1972)? To what extent do treatment-related disfigurements such as loss of hair, facial puffiness or loss of limb, result in impairment of personal identity or integrity, self-esteem and body image (Meissner, Thoreson & Butler, 1967)? To what extent does the ominous threat of death make the child's situation so precarious that future academic or vocational plans are delayed or shelved?

As noted in the Introduction (Part I), contradictory evidence exists in the research literature regarding most of these questions and issues. Some research suggests that chemotherapy and cranial radiation produce learning decrements, memory loss and reduction in neurologic functioning (Eiser, 1978; Meadow & Evans, 1976). Other research suggests that these effects are non-existent, quite minimal and/or temporary, especially after treatment ceases (Eiser & Lansdown, 1977; Soni, et al., 1975; Verzosa, et al. 1976; Zwartjes, 1978). Moreover, some of these reports argue that effects vary substantially with age of the child (younger children may be affected more strongly than older children) and with type of treatment (how much radiation or surgery). When the research focus shifts from physical and physiologic assessments to a consideration of emotional and neurologic factors, the picture is even more complex and uncertain. Not only does the disease and its medical treatment have to be taken into account, but any situation that creates sustained

personal and familial stress is bound to affect the child's normal environment, and therefore normal functioning. Moreover, repeated hospitalizations which remove the child from school for extended periods of time are bound to create school decrements, regardless of physical changes involved. Thus, what is "normal" for children with cancer may be different from what is "normal" for children without cancer. Despite these obvious factors, the most recent research suggests that the psychosocial effects of cancer and its treatment may be less than anticipated for children who are long-term survivors (Holmes & Holmes, 1975; Koocher et al., 1981; Li & Stone, 1976; Verzosa et al., 1976). Given the past decade's increase in the number of children who do survive for extended periods of time, recent research is by far the most important.

Despite these most recent optimistic reports, many of the afore-mentioned concerns continue to be present as assumptions in the research literature and medical or psychosocial commentary on children with cancer. Moreover, they appear to be present in the more general public stereotypes and expectations held for these children. We did not employ a prospective design in this study, nor did we administer measures of self concept, emotional well-being or psychological adjustment. Instead, we asked adolescents to describe in their own words whether they had changed and how, what they experienced as problems, what they evaluated as helpful behavior on the part of school staff and peers, and how well they felt they adapted when they returned to school. Clearly their comments are as much an indication of how they want to be seen as it is of how things really are. One check on the accuracy or distortion of these adolescent's self-presentations is available through the observations of parents and school staff members. Adolescent perspectives are valuable, per se, but for readers who are concerned that informants may deny some issues and present an overly optimistic view, or may distort reality in an exceedingly

pessimistic self-presentation, comparisons can be made with the reports from the school staff and parents. In this section we present and reflect upon adolescents' comments on the nature of their school re-entry.

The comments that follow were collected through personal interviews with 12 adolescents with cancer. Of this group, 4 had leukemia, 3 had osteogenic sarcoma, 2 had Hodgkins' disease, 2 had lymphomas, and 1 had neuroblastoma. In addition to these interviews, we conducted group discussions over a one month period with five other adolescents with cancer. Of this group 4 had osteogenic sarcoma and 1 had Hodgkin's disease. These adolescents ranged in age from 11 to 21. Eight of those interviewed were males and four were females; of the group participants, three were male and two female. No two students had attended the same school. Regardless of the use of a personal or group interview procedure, three sets of issues were investigated:

- 1) The quality of adjustment in the early stages of school re-entry, and factors which contributed to the ease or difficulty of re-entry.
- 2) The reactions and helpfulness of the school staff.
- 3) The effects of the illness on social and personal adjustment, extracurricular or leisure involvements and values or plans for the future.

School Adjustment Factors

Each of the 17 adolescents indicated that he/she welcomed the return to school and the resumption of an important aspect of his/her life. For 8 of the 17 informants (47%) school reentry did not pose a significant problem. In most of these cases the smooth return was a result of co-ordination between family and school, and dissemination of information to peers about the returning child. For the remaining 9 students, a variety of problems were reported: four experienced considerable teasing, especially because of hair loss; a similar number experienced academic problems, had difficulty completing assignments, and in two cases were held back a year. As one

student reported:

I got held back in one grade because I was in and out of the hospital for treatments and check-ups.

In a few cases, students reported that heavy chemotherapy schedules created short-term problems which made it difficult to keep up with school work. However, these cases were in the minority. The majority of these students felt that their academic performance did not suffer as a result of the illness. They described themselves as caught up with school work, even though it may have taken a while to achieve this status. Several even noted that school work seemed easier than before their diagnosis because of the increased concentration, seriousness, and commitment with which they now approached school tasks. In many regards, these reports are quite similar to their parents' reflections.

Of course, the total picture is not entirely rosy, and problems and disabilities were experienced by some students in school. Three adolescents with osteogenic sarcomas (resulting in leg amputations) reported problems in getting around the school. For example, one child whose leg was amputated had difficulty in negotiating crowded school halls. Nevertheless, he adapted.

I have trouble getting places, but the only time I leave early from a class is before lunchtime, because everyone runs down the steps and I have to get down before them. At the end of school, I usually wait a while and a teacher takes me down and helps me get my books and stuff.

The Importance of Good Communication

Several observers suggest that communication between the youngster with cancer, the family, the school staff and the medical staff is likely to have a significant effect on the ease or difficulty of the child's re-entry to school (Cyphert, 1973; Greene, 1975; Moore & Triplett, 1980; National Cancer Institute, 1980; Pearse, 1977). The regularity, completeness, and manner in which information is shared

among teachers, family members and other students can have a profound effect on school-related problems. In some cases, parents informed the teacher and, depending upon the efficiency of the school's communication network, information was transmitted to other teachers, school administrators, and the child's peers. In one case, very little information was given, and when the child returned to school she encountered a relatively curious and uninformed group of teachers and peers. She found this situation disconcerting, and wished that information had been shared before her return. In another case, an adolescent girl with cancer simply told one friend, who in turn activated the school's grapevine and transmitted information about her illness throughout the school. The school administrator, doubting the accuracy of the information source, initiated contact with the family to find out whether the information about the child's health status was correct. When he was able to clarify the situation to his satisfaction, the administrator prepared the school staff for what it would confront once the child returned to school.

Most adolescents felt it was crucial for the school staff to receive firsthand information in order to stem the spread of false rumors and misinformation. In some cases, the child with cancer (or even parents) did not understand totally the illness and treatment process. This can be especially likely with younger children, who may receive a simplified version of reality from the medical staff. Under such circumstances the school may need to get in touch with educational or medical professionals for more adequate information.

The key to the information-dissemination process often was seen as the school nurse, school psychologist or social worker, since persons in these roles could act as a liaison between the school, the family and the hospital (Clapp, 1976; Katz, et al., 1976; Moore & Triplett, 1980). Students did not necessarily need a nurse for physical reasons, but a well-informed counselor who understood the disease and related issues,

and who could improve information and communication. As two youngsters reported:

I wish there had been someone at the hospital -- and I know parents have been working for this -- a full-time person, like a nurse or social worker, who would come regularly from the hospital to the school and vice versa. But the problem is money. Now there is only coverage for in-patients, and that outreach role is not built into the system.

Before you know it, everybody knows, or thinks they know. Then they start calling you to find out if what they heard was true. Communication is very important, very early on, so things don't get out of hand.

Reactions of the School Staff

The adolescents generally felt that the responses to them of school staff members were quite favorable. For example one student commented:

My teachers have been very good and understanding.

Some students found the school staff eager to help, but recognized and tried to avoid becoming too dependent on teachers.

I would tell my teachers not to baby me and that I was just like everyone else.

I tried to keep my problems from them so I wouldn't develop a crutch to lean on.

Despite these defences, several youngsters experienced teachers who tended to be overprotective.

I felt I got a little teacher overprotection. I usually ended up as a coach in gym. I couldn't do a lot of things that the other kids did. I got an automatic 'A' in the course.

Students' favorable evaluations of the school staff occurred for different reasons. Some students viewed their teachers favorably because of flexibility with respect to deadlines for schoolwork while they were in treatment, or because their teachers actually helped them complete work in the hospital. In one case, a student missed 2-1/2 months of school during her 10th grade, but was able to complete the most essential course work. Teachers also were rated favorably when they took the

initiative to talk to the class about the illness and to help the class understand cancer and its treatment. These actions by teachers made it much easier for peers to accept and to be direct with the student with cancer upon his/her return to school.

Obviously, not all students were blessed with active and sensitive teachers. Some were in schools with less cooperative staffs and felt that this situation placed an additional burden on them. As we reported in a prior section, parents from lower class backgrounds, or whose children were not doing well in school before the illness, reported more negative experiences.

Our adolescent informants also suggested several ways teachers might be particularly helpful to students with cancer. Their major message was that they wanted to be treated normally. When help was given, they felt the goal should be to foster independence and their ability to fit in with their peers. Other practical suggestions students had for educators included:

- Taping class lectures and making them available to students who are at home or in the hospital.
- Allowing students to focus on main concepts or skills when time is limited and omitting supplementary requirements.
- De-emphasizing the importance of grades
- Using the discretionary power of the school principal to waive formal examinations if the student is hospitalized or undergoing chemotherapy.
- Sending cards to the student when hospitalized.
- Providing the student with an extra set of books to leave at home if the student is on crutches.
- Demonstrating the use of prostheses to the class.
- Maintaining openness, honesty, and direct communication the student.

In the final section of this report we include a longer list of suggested actions, culled from various sources.

Psychosocial Development of Students with Cancer

The extent to which adolescents are able to continue their involvement in activities they enjoyed prior to diagnosis is a good index of the degree of disruptiveness of childhood cancer, and may be a good predictor of long term adjustment. In the interviews, we obtained evidence of substantial continuity from most informants, and this included youngsters who had relapsed. In particular, 4 of the 5 adolescents participating in the extended discussion group had been highly athletic and had participated actively in extracurricular activities before their illness. They showed similar patterns after diagnosis and treatment. One group member had been a cheerleader and a member of the gymnastic team prior to her diagnosis with osteogenic sarcoma. After the removal of her leg, she adapted and continued as a cheerleader. She felt this step important for her own well-being, as well as for its salutary effect on her peers. As she noted:

Students with cancer should stay involved in school activities such as band or other clubs. Then other students would see that they (children with cancer) are fine and that they don't have to be worried or fussed over.

A 13-year old male with osteogenic sarcoma, also an amputee, learned to ski and ride a bike with one leg. His accomplishments evidently inspired other amputees with whom he had contact to do the same. On the basis on this limited sample, we believe that the experience of cancer, even when it involves severe physical impairments such as the loss of a limb, need not necessarily diminish students' interest in academic pursuits nor limit their participation in extracurricular activities. To the contrary, in the face of physical handicaps, many students appear to find creative ways to adapt and normalize their lives.

The quality of interpersonal relations is another domain of psychosocial development that may be affected by the experience of cancer. We asked youngsters

specifically how they related to their peers and how their peers acted toward them. The adolescents in our sample showed few signs of social withdrawal. To the contrary, they expressed a strong desire to resume relationships with and become part of their peer groups as quickly as possible. Some felt they were treated quite normally, "like anyone else". Sometimes, however, the reactions of peers were characterized by awkwardness, uncertainty, and over-cautious behavior which strained relationships. This was most likely to occur when friends or classmates were not well-prepared for the youngster's re-entry. Withdrawal and misplaced concern by peers sometimes transformed previously free flowing and intimate relationships to distant and strange ones. Two adolescents commented on this awkwardness or strangeness as follows:

When I went back to school, I felt that students were shying away from me. I thought they were ignoring me at first, but now I realize they just didn't know what to say.

Well, I suppose that some people avoided me because they were embarrassed and didn't know what to say, and others went out of their way to talk to me, and some people treated me the same way.

Two female adolescents felt that people shied away from them at first, not knowing how to react, but eventually returned to normal when they realized that they were still "the same people", and that they were going to continue living their lives as normally as possible. Sometimes just the newness of the situation made it difficult. Peers did not know how to behave or what they could expect from the adolescent with cancer. Often they waited for signals about how they wanted to be treated, and then responded in accordance with those signals.

When I got out of the hospital I was invited to go to a party. I knew that a lot of people there were really scared to come up to me and talk to me. . . I spent that night at the party sitting in the kitchen. But when people found out I was still the same person, and did everything I did before, and was going to keep going on with my life, they were more open and more comfortable. There

were some, though, who never got to that point.

Once peers knew what to expect they began to act more normally. However, it generally was up to the ill youngster to establish the terms of normality, and to invite continuity in peer relationships.

Thus, in relationships with close friends, it was not always or only the case that healthy peers provided emotional support to the child with cancer. On occasion, the adolescent with cancer assumed the role of comforter and supporter of others. One very perceptive adolescent described the burden that stemmed from his concern about the psychological well-being of his friends, especially in the early stages of the illness.

It was hard enough trying to keep myself together. . .I felt like I had to keep my friends together too. Whenever we got together, they were so worried about me that I had to spend time calming them down, telling them that I'd be okay.

Another adolescent described his feelings of rejection by his friends. Although this rejection was not direct, he came to feel as though he was a liability to his former companions with newly developing heterosexual interests.

When you're sixteen and looking for girls, and you don't have a leg, you're not exactly the most popular guy to hang around with.

Sometimes the awkwardness, fear or rejection of peers took more direct forms, such as in teasing. Teasing responses were much more often reported by younger children than by adolescents. Moreover, peers often mobilized to prevent or to counter teasing when it occurred. As in prior reports from parents and teachers (see Sections II and III of this report), open communication and a pro-active stance appeared to reduce the incidence of peer teasing.

Adolescent informants also were asked about the long term effects of cancer on their career aspirations and life plans, and were asked explicitly to discuss the effects of cancer on their educational and occupational futures. Almost all

youngsters we talked with were optimistic and "upbeat". When asked about the future, they all had some concrete plans and some vague dreams. Two had already enrolled in college and several planned a college education once they finished high school. Those who were uncertain about their plans appeared to have a typical adolescent vagueness, not clearly tied to illness or treatment issues. These results seem quite typical of other recent empirical research that reports direct conversations with adolescents with cancer. Although they may experience pain and fear, and at times anxious concern, those in remission often deny a very negative impact of their illness. Whatever the true nature of their internal feelings, most adolescents present themselves as coping positively, being quietly courageous, and going on with as normal a life as possible (Fochtman, 1979; Koocher, et al., 1981; Zeltzer, et al., 1980).

In assessing the general impact of cancer on their lives, the students participating in the discussion group and the interviews all felt they had grown and matured considerably. New insights and strengths were reported.

I accept a lot more challenges. You feel you can do more and you're more self-confident.

Many responded that they now felt more serious about their lives, that they worked harder, and that they put more energy into striving for their goals.

All of this has helped me realize that there are a lot of little things out there that we take for granted, that we ought to stop and look at. The other night, I was going home and it was cold out, but there were so many stars out I had to stop and look at them. I think that before, I would have just jumped in the car. I enjoy each simple moment more.

Conclusions.

This admittedly limited sample of 17 adolescents clearly verifies our expectation that the experience of cancer carries emotional stress and trauma for its young

victims. Moreover, it continues to document the ways in which educational institutions often are unprepared to facilitate effective re-entry. However, it also indicates that childhood cancer is not inevitably debilitating on an emotional or psychological level; it does not necessarily result in an impairment of close relationships, nor the forfeiture of career aspirations and dreams about the future. We have found no evidence which would lead us to conclude that emotional maturity, a capacity to adopt adult rules, and a high achievement orientation is any less likely to be found in these adolescents than in adolescents without cancer. This is especially true for adolescents who are in remission and doing well physically. The role of adequate preparation and action to preserve prior outlooks and relationships appears essential, and serves to emphasize the importance of the family, the medical staff and educators in helping to preserve these youngsters' prior quality of life. In these terms, much of the normal (and sometimes even more positive) developmental pattern reported here is probably as much the product of pre-illness socialization and disposition, and family-community response, as of the experience of cancer itself. There appears to be a high degree of continuity in the psychosocial development of children with cancer, and the disruptive effect of the illness experience on such development may be less unique and severe than some earlier observers have expected or predicted.

As we indicated previously, the literature on childhood cancer is quite mixed on this last point, on its general evaluation of the psychosocial impact of cancer on youth. Several studies cited earlier argued that significant negative impacts do occur, and have lasting consequences for self-esteem, body image, health anxieties, peer adjustment and general level of emotional maturity. Other studies emphasized the apparent normality of seriously and chronically ill youngsters on these dimensions. Without denying the stresses and problems noted by others, they conclude that many

if not most surviving youngsters are quite comparable to their peers who do not have cancer.

The more positive studies appear to have been conducted more recently, with better samples, and by researchers especially skilled in social research techniques. Earlier studies, often conducted with small numbers of terminally ill youngsters, or with youngsters facing much more pessimistic odds for long-term survival or recovery, suggest more negative impacts. The earlier studies, moreover, were done at a time when practitioners and researchers were trying to alert the professions and the public to the psychosocial problems of these youngsters and their families, and of the need to attend to this aspect of treatment. More recent studies have taken the need for psychosocial treatment as a given, and often have sought to reassure frightened families and the general public that these youngsters are quite normal. Finally, those studies that talked directly with youngsters, and that took their own reports and reactions at (more or less) face value, more often found positive adjustment than did those studies that undertook psychological interpretations of youngsters' self-reports. It is possible, of course, that the more positive studies have encountered youngsters who are denying the full impact of the disease on their lives. Denial, of a moderate sort, may be a healthy and effective coping mechanism, as well as a common one (Friedman, et al., 1977; Lazarus, 1966). When adolescents combine a moderate level of denial with a strong desire for normalization, we may expect the self-presentations reported here. Fochtman in fact, reports one teen-ager's comments to the effect that "I am living with, not dying of, cancer (1979, p.31)". That orientation, and behaviors consistent with it, certainly are reflected in the lives of the teen-agers we interviewed.

The small data base and mixed inquiry methods used in this study cannot attempt to resolve these critical questions. In fact, these questions by now are as

much an issue for the sociology of science as they are for people studying the psychosocial situations of ill youngsters. The "whys and wherefores" of this controversy, and the delineation of audiences committed to different sides of the argument, represent important problems in scientific inquiry. Our findings do affirm many of the more recent studies, especially those that utilize youngsters' self-reports. Whatever the "true" state of affairs of these youngsters' psychological processes, it is clear that they wish to present themselves as doing well, and wish to be treated as doing well and being normal by others.

PART V. MEDICAL ASPECTS OF SCHOOL RE-ENTRY

As we begin to talk about the medical issues surrounding cancer and children, the first real question is, what is cancer? If I were to ask any number of people in this audience what cancer means to them, I'd get a variety of different answers. Generally speaking, when we talk about cancer we mean a process in the body in which a cell or population of cells has gained the ability to grow in an uncontrolled fashion, or has escaped the usual control methods the body uses to check the population of cells. Cancer is a single term that really refers to a variety of different diseases. There are tumors of any number of different tissues and organ systems that would fall under the term "cancer." Most of these tumors are otherwise called malignant tumors or neoplastic tumors. Their significance is that these tumors have an ability to grow out into the tissues surrounding the site of origin, to spread to other parts of the body, and to invade normal tissues. That provides the devastating effects of a disease like cancer.

Current Progress in Treating Childhood Cancer

Pediatric hemotologist-oncologists generally are pretty busy. That doesn't really imply that the problem of childhood cancer is overwhelming; the numbers of children with cancer are certainly far less than the numbers of adults with cancer. Nevertheless, it is a major problem because children have so much potential to achieve. As a result, there's a lot of interest directed towards improving treatment results with cancer.

If we were to look at the population of patients that we treat with cancer, about half have acute leukemia. The other half is comprised of a variety of solid tumors - brain tumors, tumors of lymph glands (so-called lymphomas), Hodgkin's disease, bone or muscle tumors, and tumors of the kidney or other organs. The sub-

types of cancer just can't be lumped together as is often done in some of the popular press and the news media. The tumors effect different areas of the body, hence, their side effects and treatment are going to be different. Equally as important, with present-day therapy, different tumors have widely varying prognoses. As a result, a population of children with one kind of tumor will do better than another population with a different type of tumor.

To give you a rough idea of how prognoses have changed, I can mention a few of the sub-types of cancer. Wilms' tumor, a tumor of the kidney, is fairly common in young children less than age 3 or 4. Two decades ago, Wilms' Tumor was highly fatal, with a disease survival rate about 20% at 5 years. Now 70% or 80% of those children will be disease-free over that same period of time. With acute leukeumia the same kinds of results are evident. In the pre-treatment era, maybe 30 years ago, leukemia was an invariably fatal disease. There were reports of occasional spontaneous remissions, but the disease-free survival at 5 years would be less than 10%. Now that is in the order of 55-60% at 5 years. Those notable improvements, are true of a variety of solid tumors and lymphomas.

It's important to keep in mind, when we're thinking about children with cancer, that there's a lot more optimism surrounding these illnesses than was present a couple of decades ago. We try to maintain that optimism at the time of diagnosis, with a bit of realism that not all children are going to be cured. This optimism is part of our approach to managing the child and to interacting with the family. Thus, we encourage a return to a fairly normal habit of life for the child, both within the family and in their neighborhood and the school system. There are several advantages to this approach.

School certainly is a main part of the child's life, for a variety of very important reasons. Both the intellectual and social maturation that the school

provides is essential, and it is equally as essential for a child with cancer who has the potential to survive for a normal lifetime. Some of the old concepts about cancer and children, and limits on the usual types of school activities, have to be modified somewhat. The other important aspect of the school is that it is future oriented, and thus fits with the optimism we try to generate in the hospital. If there are goals that the child can aim towards, if things are maintained in a fashion they were accustomed to, real progress can be made.

Returning Children with Cancer to School

Are there any obstacles to school attendance once children have been diagnosed and begun treatment? There are some issues related specifically to the cancer or to the therapy directed against the cancer. Initially, a week or two is spent in the hospital, for diagnosis and the initiation of treatment. There is an antecedent period, of course, when the child may not be feeling well. The duration of the treatment of a child may undergo is highly variable, depending on the type of tumor or leukemia the child has. Most of our therapy runs anywhere between a year and a half (sometimes shorter than that) to three years. Most of that therapy isn't intensive enough to require continual hospitalization. For example, nearly half of our patients have acute lymphoblastic leukemia. After you get beyond the first month or two, most of those children can be treated entirely as outpatients, and such treatment is not unique to that disease. There are a variety of other children who can be treated largely as outpatients. There's another population of children who have to come into the hospital for 3-5 days at a time, once every 3-4 weeks. It's highly variable, and it's going to be important to individualize with patients, and to talk to physicians who may provide some clue as to what the sequence is likely to be with regard to attendance at school.

There may be a variety of disabilities associated with tumors. The one that

may be most prominent occurs with the subset of brain tumors, and that can present a whole spectrum of symptoms. Some of those children, fairly soon after diagnosis and initiation of treatment, are able to return to school, and many are not. In addition, many of those patients who do return will have a variety of physical handicaps, some permanent and some transient. That may influence their ability to reintegrate themselves into a normal pattern of existence. Beyond brain tumors, some of the bone tumors and occasionally some other soft tissue tumors do require amputations or removal of an extremity. That's another issue that can be a factor in determining how quickly a child will be able to return to his normal lifestyle. The other tumors don't usually cause physical handicaps.

There may be some serious side effects of chemotherapy, and they cover a wide spectrum of problems, including whether a child can attend school. Many of the agents that we use to treat these tumors and diseases can produce nausea and vomiting. The nausea and vomiting is usually temporally related to when the drug was first administered, and should be a fairly abbreviated problem lasting no more than a day or two beyond the completion of the course of chemotherapy. Blood count suppression, or bone marrow suppression, with resultant abnormalities in the blood counts is another problem we encounter in our management of the patients. Many of these children will not feel energetic or well, and some may be at high risk of infection. All these side effects potentially can influence what recommendations would be made to the family as to how the child should interact with the environment. These risks have to be weighed in our assessment of what a patient should or should not do, and they should be a consideration in the school setting.

For example, we use the white count as an index of the likelihood of infection in a patient with cancer on chemotherapy. If the absolute white count, or the absolute neutrophil count (the neutrophils being these white cells that eat up bacteria),

is very low (500 cells per cubic millimeter of blood), then we know that those patients have a notably increased risk of bacterial and fungal infection. For that group of patients we might have some restrictions in terms of their ability to attend school. The white count shouldn't be a major issue in most cancer patients on chemotherapy, but it occasionally can be.

Some Special Problems

In the school setting, there are a couple of things we are particularly concerned about. Two common children's illnesses we are worried about are viral infections--chicken pox and measles. Chicken pox is probably the preeminent disease to worry about in the school setting. It is an illness that most children get and that most children deal with quite effectively. However, immuno-compromised patients (particularly leukemic patients) are going to be at risk from chicken pox. If they contract the disease there is an increased risk for serious morbidity and occasionally mortality. Probably on the order of less than 5-10% of patients with malignancy and chicken pox will have a major problem, but nevertheless it is that 5-10% that we would like to avoid. The problems that can arise in these children as a consequence of chicken pox, unlike normal children, include pneumonia, hepatitis or an infection in the central nervous system. We do have some things we do for these patients, and hence we'd like to know immediately after an exposure so that we can administer immune globulin and attenuate or prevent the severity of the illness. The family and medical staff must know within 48 hours of any exposure to chicken pox. Chicken pox is infective for a couple of days before the rash becomes apparent, so it may be important to know when a parent calls in and says "my child developed a rash today," whether the child was infective yesterday or for the past several days. If there was an exposure of the child with cancer within two days of the onset of the rash we (the parents and the medical staff) should know about. Of course, if the child with

cancer comes in contact with the infected child while he or she has the active rash, we should know about that as well.

Measles is another disease that we would like to know about in the same sort of way. We do have an immune globulin we can give for that. A less serious infection that might arise in the school setting is mumps. It, too, occasionally can produce disseminated illness in other parts of the body, but generally speaking that hasn't been a problem in the children with cancer that we take care of.

We would follow the usual sorts of recommendations with regards to strep throats as for any other child exposed; there's nothing special about that. Usual types of upper respiratory infections are not a major problem. In general, we try to minimize contact between our patients with children with serious bacterial infections, like pneumonia. But those children with cancer who are in the greatest danger of infection (i.e. those with low blood counts), are not likely to be going to school anyway.

Some of the patient concerns we encounter about school are related to bodily change or body image changes occurring with regard to the therapy we're delivering. One side effect of our therapy often is hair loss, and that's an issue more for some patients than others. Some patients are completely comfortable with their hair loss and don't grapple with that too much, and others deal with a lot of trauma in this regard. Moreover, this may differ for children of different sexes and of different ages. Something we often do for patients who have those concerns is to obtain a hairpiece or wig. Hair loss usually is a temporary phenomenon, and hair usually regrows in a pretty similar fashion to the way it was previously.

We have already mentioned the loss of an extremity, and that holds obvious significance relative to body image. Most of our patients who do lose an extremity in the course of their treatment usually apply a prosthetic device for the extremity

that is missing, particularly if it's a leg. Weight gain also is occasionally a problem with patients, particularly leukemic patients, whom we might have on prednisone.

School-Family-Hospital Cooperation

In the school setting, it would help to have the staff and students prepared for some of these side-effects with which the child may return to school. We in the medical profession may be able to help by having better communication and interaction with the school system. We certainly would welcome such initiation, because we get so caught up in taking care of the medical needs of the patients in the hospital that we neglect these issues. We'd be glad to help. The way things are set up right now, we don't have somebody who can come out to the school and visit with teachers. The team in the hospital consists of the physicians, nurse practitioners, social workers, and perhaps the chaplain. But there is no one who is specifically assigned the task of coordinating the hospital, the family and the school. That isn't to say that we would not be willing to come and talk about a problem, or to talk over the phone, but there isn't right now any readily defined person who would do that.

Occasionally educators experience problems in deciding what kinds of standards to enforce for children with cancer, particularly in the first few months after diagnosis. Some allowance probably has to be made for these children spending a modest amount of time in the hospital, or traveling back and forth from the clinic. Probably the best thing to do in that circumstance is to get a feeling for how much time the child is spending at the hospital, and how much time the child is spending in the treatment program. In some cases, we can help decipher why the child is having problems in school; we could do some further testing that would see if there is something we can do. If there seems to be a problem after that, we do have facilities available for assessing psychological needs of children to see if there are

any underlying problems.

We don't know, of course, what the long term effects of all the treatments are on school performance. Since the treatment results have improved really notably in the last 10 - 15 years, and treatments are changing all the time, long term effects are only now beginning to be assessed. One group of patients we are studying intensively right now is a group of our leukemic children who were treated between 1972 and 1975. Within the next few years we might have some definitive answers on whether there really are tumor or therapy-related learning disabilities or intellectual dysfunctions. The only thing right now that I could recommend would be to take a step-wise approach: most of the children in the induction period - the first two months of their treatment - may not be pushable; most of the children who are in maintenance, would be fairly ready to be pushed.

There also are parental concerns concerning the return of the child to the school system. One I have encountered is, as expected, a protective approach to the treatment of the child in the home situation. At the time of diagnosis, trauma surrounds the child and the family. In the initiation of therapy, we try to put the risks in perspective, because 90% of our children can go back to school soon after diagnosis and the initiation of treatment. On occasion I have encountered families who were unwilling to let their child go back to school even for the first year after diagnosis. This is a delicate situation and we could use some help from you in this area.

Some teachers and school administrators may be concerned about unexpected problems in the class itself. I think that the likelihood of any sort of acute problem in the classroom setting would be quite small. Occasionally the child will get ill, and if the child in the classroom complains of feeling ill, and is checked by the school nurse and has a fever, the parents should be advised. There are few things that

require immediate attention. Occasionally, a child might get nauseated or vomit from the treatment that they might be receiving. Most illness of that sort occurs at the time of intravenous medication administration, which we do in a clinic or in a hospital.

Finally, there is very little risk to any of the other children in the class from the child with cancer. As best we can tell, none of these tumors have been demonstrated to be infective or transmissible in any way. In the past there has been concern about the link of Hodgkins disease and of other non-Hodgkins lymphomas to infectious mononucleosis and other viruses, but such a link is speculative and not widely held. This is the only situation that I can think of in which any infective has been associated with a tumor. Consequently, the risks to other children in the class is very small.

In sum, the risks to the child with cancer in school are probably not great, unless they are exposed to a child with chicken pox or measles; or perhaps if their white count is very low. That is not something most of you have to worry about in the school setting, because we are quite careful about our care of these patients. Any limitations and risks that a particular child will face are going to be significantly tailored by the type of problem that the child has, the type of chemotherapy the child is on, or the stage of the disease. There is a wide variability, even within a given disease, which influences how they do. All of those things have to be weighed in the overall equation.

Conclusions

I'll close with comments on the process of school re-entry and reintegration. We would be glad to help with that process: sometimes we neglect it. We can help by defining what the illness is, what the extent is, and maybe give you some clue on the prognosis for that type of tumor in the long run. We can talk about the type of

therapy that the patient will be getting and what the potential side effects from that therapy are. We can talk about what physical limitations might be expected in the short or long term. We can share what we have told the child about his diagnosis, or what the family has told the child about the diagnosis, because that is potentially a major issue in the school setting or in discussions with classmates. Under some circumstances, information could be given to the class about what's wrong with that child, what type of treatment is involved, and what kind of stress the child might be under. These acts could provide other children with some useful information that would help everyone. Of course, all of these things should be done with collaboration and permission of the medical staff, the school staff, the family and the child.

It is important to maintain a positive attitude towards the child's prognosis, unless we have clear indications, that we share with them and with you, that something is going wrong. Certainly at the outset it is vital that we all maintain a positive attitude about the child's return to school, and what the long term outlook holds for that child.

PART VI: CONCLUSIONS AND RECOMMENDATIONS

The multiple perspectives provided here demonstrate a remarkable consistency in their perception of the re-entry problems that exist, and of the ways in which all parties would prefer to deal with them. All seem to argue for normalization of the child's environment and experience, and for direct and well-coordinated communication among various persons and institutions. Children, parents, siblings, school personnel and medical staff are bound together by their common concern for the physical and mental welfare of the ill child, and by their own attempts to deal with the stresses and problems involved in childhood cancer. One optimistic trend is that more people treat the real issues of school re-entry as ones of improving the quality of life of survivors rather than of accomodating to illness and death. However, each group has its own set of problems to deal with, and therefore each brings a slightly different focus to the discussion of school re-entry.

In thinking about the school re-entry of children with cancer, researchers have suggested several potential problems. Because these children may be emotionally fragile, concern arises about their psychological health, future development and school phobia reactions. Some medical and educational professionals are concerned especially about increased school absences and about other impediments to academic achievement. However, in our study, these issues did not emerge as major problems. Absences were reported more often by parents of children who had relapsed, or who had been hospitalized often. But there were few reports of widespread academic problems, and neither teachers, parents nor students noted gross signs of developmental arrest or psychological distress on the part of the adolescents included in the study. Most adolescents were able to maintain continuity between their interests and level of activities prior to diagnosis and treatment, and after. This

view is not pollyanish; it does not deny that these children are engaged in a difficult struggle, and that the persistent and unremitting demands of illness and treatment represent physical, emotional and social burdens. However, parents, teachers and students in this sample all reported that most students responded to their medical situation with equanimity and adapted positively.

All groups of informants -- teachers, parents and adolescents -- agreed that some of the greatest problems were related to the reactions of others -- audience reactions. For instance, the most frequent problem reported by parents and teachers was teasing and social rejection of the child by peers. Adolescents also described the reactions of their peers as their most difficult problem, especially in the early periods of school re-entry. Friends' rejection and overconcern both proved to be troubling. Occasionally, even parents of other children were involved subtly in the isolation of children with cancer.

A second major problem emerging from the interviews pertained to teachers' reactions to children with cancer. Many teachers went through the same stages of shock and grief as did parents. Unfortunately, teachers generally found fewer people ready to help them deal with their reactions. Occasionally, these reactions were exacerbated when teachers had children of their own, so that they identified very strongly with the sick child and her/his parents. Teachers also reported ambivalence at seeing children as innocent victims and at the same time as presenting problems to be avoided and feared. On occasion, these mixed and confused feelings led to approach-avoidance reactions that confused children, their parents, and peers. In one of the earliest commentaries on the school re-entry of children with cancer, Cyphert (1973, p. 216) described teachers' feelings in quite similar terms:

We don't know what to say to him, so we say little; we fear that we might get asked an uncomfortable question so we don't permit the opportunity for questions; we overempathize because we identify the child with cancer with our

own loved ones.

A lack of contact and communication between the school and the hospital also was reported as a problem by parents and teachers. Teachers reported discomfort due to their lack of knowledge about the disease in general, as well as the particular child's current health status, and thus what to expect once the child returned to school. This made it difficult for them to plan and to make judgments about how flexible or demanding to be of the child. Because they had little knowledge about the course of the illness, or the effects of the treatment, they were concerned about misinterpreting the child's behavior, and either unnecessarily attributing behavior and affect to the illness, or inappropriately excusing behavior they otherwise might not tolerate. Lack of contact with the hospital staff also made it difficult for educators to coordinate educational plans for children hospitalized for long periods. Once the child returned to the community, teachers knew little about their progress or the skills developed during periods of hospitalization. Sometimes parents had the information to fill the gaps in teachers' knowledge, but often they did not.

With particular regard to classroom issues, both teachers and parents discussed the importance of achieving a balance between ignoring and overprotecting the child with cancer. Many parents reported that they felt it was difficult for educators to achieve this balance, and that they were concerned about the school staff's insensitivity or disregard for their child's special needs on the one hand, and about "babying" and spoiling their child on the other hand. Teachers and administrators readily agreed that they experienced difficulty in finding a correct balance, and that "treating the child normally" was in fact quite a complex task.

Normalization requires that children with cancer be provided with opportunities for experiences as identical as possible with those of other children. Normalization also requires avoidance of stigma and negative social reactions which unduly single out ill children, and which deny them access to available and important resources.

Thus, it often involves challenges to stereotypes and behaviors which ipso facto suggest that children with cancer are fragile, incapacitated or doomed to failure in school. In some cases, of course, lowered or relaxed requirements and special care or treatment are necessary and appropriate. Normalization does not mean denial of the seriousness of these children's conditions, nor of physical or psychological limitations which may affect the administration of classroom rules and regulations. Most importantly, it does not mean treating children with cancer like every other child. In one specific example reported by parents, it does not mean requiring that the hospitalized child take his final examination at the same time and place as all other students in the class.

Normalization prescribes the desirability of responding to children with cancer on the basis of fine discriminations and judgements about each child's actual emotional development, observed physical capacities and demonstrated intellectual abilities and interests. Ignoring or overlooking each child's unique physical and emotional stress is not normalization; it constitutes refusal to deal with individualized learning styles and agendas. On the other hand, automatic and dramatic changes in the rules of the game are not normalization either; they may have unfortunate secondary effects of convincing children with cancer (and their peers) that they are no longer part of the same game as are others.

Obviously, parents and educators did not always agree on how the school staff should have responded to their children's situation. Parents seriously concerned about the school's response to their child seemed to adopt one of two coping strategies: (1) focusing on the child's behavior and urging him or her to work harder, relax more or ignore peers' and educators' negative responses; or (2) focusing on the school's role and either urging educators to maintain or alter requirements or taking a pro-active stance in creating supportive behavior from teachers and classmates.

Especially when such issues were raised directly by parents, teachers wanted to be helpful, or were willing to take the risks involved in reaching out to others. Some hesitated to step outside of their professional roles or to risk intruding into a child or family's privacy. This was especially the case if the family did not take the initiative in asking for help. In this regard, teachers experienced the same dilemmas as close friends and neighbors of the family, who also expressed confusion about providing unasked-for help. A number of these issues and problems seemed to be more potent for those children from families with lesser educational backgrounds, or who were not doing well in school prior to diagnosis. Parents who were less comfortable with the school to start with, or whose children were not performing well in school, may have had a harder time creating effective relations with the staff. Parents with lesser educational backgrounds reported receiving less help from the school staff in general. Given the enormous scholarly literature that has developed regarding the differential experience and treatment of school children of various races and economic classes, these problems seem quite consistent with the broader problems of inequality in our society and school systems.

Recommendations

The interviews with parents, teachers and adolescents not only yielded rich information about school re-entry problems; they also provided useful suggestions for dealing with these problems. The recent history of efforts to change or improve educational systems (or medical institutions and many other human service agencies, for that matter), gives us little confidence that an isolated series of recommendations, per se, will make much difference. Eventually, recommendations must be integrated into a coherent plan for change, and acted upon by several groups working in concert. In some cases, collaborative problem-solving efforts involving parents, school staffs, and medical personnel will be effective; in other cases parents

will have to advocate strongly, and bring pressure to bear on other parties (Crowfoot, Bryant & Chesler, 1982). Regardless of the change strategies involved, new school or new school-home-hospital programs must start from a sound understanding of problems and goals. Thus, on the basis of comments from the interviews, and the reactions of conference participants, the following recommendations can be made for school staffs, parents, and medical staffs.

Recommendations for the school staff. Advanced preparation can make a substantial difference in the ease and effectiveness of school re-entry for children with cancer. Such preparation might provide teachers and school staff members with information about the illness, course of treatment, and potential effects on the child's behavior in the school. Some of this information can be provided by parents, but many teachers would prefer receiving it from medical sources. While written information can be helpful, it is our view that meetings with nurses, social workers and doctors on the hospital staff are essential.

It is important for educators to acknowledge their personal stresses and emotional reactions to childhood cancer. Only then can they search for someone within their family or school with whom to share these feelings, and to find resolution. However, educators indicate quite clearly that these issues are not merely personal in nature; addressing them requires attention to the organizational structure and operations of local schools, and to the context within which school staff members' work. In this regard, it appears important for teachers and principals to build an organizational climate in the school that supports every teacher's classroom efforts and protects them against undue stress. Such an environment can help teachers share their classroom management problems with colleagues, and get assistance in planning how to normalize the classroom experience for the child with cancer, and for classmates, while attending to the ill child's unique needs.

With greater understanding of the medical and educational situation, the school staff can take the initiative with parents in opening up communication and maintaining direct, ongoing contact. Parents generally are engaged deeply in monitoring their child's medical status, and are able to communicate this information to educators if lines of exchange are kept open. In this way, information about the child's emotional or psychological status and needs also can be shared openly.

Teachers and school administrators can prevent problems by preparing classmates for the return of the child with cancer to school. For example, classmates can be told about the ill child, that he or she may have lost hair, or may appear obese, or may have lost a limb. This sort of information-sharing and open discussion might forestall some gawking stares and teasing, and some students' fears or anxieties about speaking directly with the child. In some cases, other children and parents might be forewarned that cancer is not contagious, that radiation treatment does not pose a danger to their own children, and that they ought to keep the school informed regarding infectious illness that their children bring to school. Classmates also can be involved in discussions of cancer and in science projects that increase their understanding of the illness. Many things can be done in and out of the class to avoid isolation and exclusion of the sick child from school events. Even when the child is separated from the class because of hospitalization, some contact should be maintained by teachers and classmates. Only an active and encouraging stance by the school staff can ensure that this psychological lifeline is maintained.

Recommendations to parents. It is critical that parents play an active role in the school re-entry of their children: it may make the difference between good and poor adjustment and achievement. In many cases, the school staff will respond favorably to parents' requests and desires. In some cases, parents may have to become more active and perhaps adopt an advocacy role to help develop a favorable

school situation for the child.

Because they spend so much time with the child, and know the child better, parents have insights that may be useful to teachers in helping them to decide how to help the child grow academically. Often, advance warnings to the school staff of events which may affect the child's behavior can be useful. This can be managed by parents providing information about external events that might cause a child to be upset or in an unusual mood, or by acquainting the staff with the child's medication and hospitalization schedule. Regularity of contact, in this case, is essential. Parents must appreciate educators' need for information about childhood cancer and treatment, and the fact that teachers struggle with their own emotional reactions in dealing with the child. In addition, since many educators are ambivalent about being overprotective, or seeming to show a lack of concern for the child, parents can help them make these discriminations and decisions.

Parents also can help inform and mobilize the friends and/or classmates of their children re-entering school. Visits to classes to inform or reassure other children, parties to integrate the child with his/her peers in a sociable environment, and meetings with classmates' parents all may be useful acts.

In some situations, it may be up to parents to solicit or encourage the involvement of medical personnel in helping to plan or manage the child's return to school. As the natural link between the community and the hospital, and the hospital and the school, parents are in the best position to create or maintain an open system of communication and contact among the various actors.

Recommendations to the medical staff. The medical staff has a vital role to play in the school re-entry process. As Dr. Hutchinson's presentation (Section V) indicated, they typically encourage parents to help their child return to school as quickly as possible. In addition, they help parents keep track of and respond to

health problems that should keep a child out of school at times. These professionals can be of great help to parents and teachers by sharing information regarding the child's health status with the school in a way that is understandable and useful to a lay audience. The medical staff also can allay educators' personal concerns and provide reassurance about steps the school is taking to help the child. Clearly, the problem is not merely a lack of technical information; to be helpful the medical staff also must assist educators in dealing with their fears, stereotypes, and concerns about the reactions of others (other students, colleagues, etc.). Discussions of specific techniques of behavior management and classroom organization also are necessary and appropriate. Currently there are several good models of such medical outreach in practice. At Philadelphia Children's Hospital this function is carried out in a systematic fashion by the social work staff. Alternatively, at Children's Hospital at Stanford, the discharge nurse on the pediatric hematology-oncology unit serves as the liaison between the hospital and school and provides consultation to family and school on re-entry issues. Other hospitals fulfill these functions in various ways: some do not. Outreach by the medical staff is a critical ingredient in helping the school staff anticipate and plan adequately for the child's return to school.

The experience of childhood cancer is shared among many people. At each stage, concerned and well-intentioned persons are involved in doing whatever they can to maintain a high quality of life for the ill child. A major obstacle to achieving that goal is the tendency on the part of each of these parties to view their contribution in isolation from others. Significant strides can be made toward successful school re-entry if greater attention is paid to coordinating the efforts among family, school, and hospital. Only through open and regular contact between the medical care organization, the school and the family can a partnership be

developed that will make the child's re-entry as productive and comfortable as possible.

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APPENDIX A: Agenda for the Michigan School Conference

CONFERENCE ANNOUNCEMENT

SCHOOL TRANSITIONS OF CHILDREN WITH CANCER

sponsored by

Share, Families of
Children With Cancer

Department of Psychology
University of Michigan

Department of Sociology
University of Michigan

EAST CONFERENCE ROOM (4th Floor)
Rackham Bldg., 915 E. Washington St.

Friday, November 20, 1981

Schedule:

9:30 a.m.	Registration	12:30	Lunch
10:00 a.m.	Medical issues in school transitions	1:45	Preliminary Findings Research on experiences of Family, School Personnel and Adolescents
11:00 a.m.	Panel - School Experiences of Adolescents Panel - Parent of Young Children Discussion	2:30	Workshop: Solving Transitional Problems
		3:50	Concluding Remarks

Conference Planning Group: Oscar Barbarin, Mark Chesler, Elaine Selo, David Aberdeen,
Sandra Bermann, Linda Bronfman, and Diane Hughes

APPENDIX B: Announcements of Other School Conferences

WORKSHOP FOR SCHOOL PERSONNEL: THE IMPACT OF CHILDHOOD CANCER

Saturday, April 17, 1982 8:30 am - 4:30 pm School of Nursing 729

AGENDA

1. Registration- coffee, tea, danishes provided
2. Introduction to cancer (the treatment team, philosophy and care, type of cancer, causes, treatment, side effects, questions)

BREAK

3. Reactions: sharing the experience of having a child with cancer in the classroom: small group discussions
4. Psychological impact of a child with cancer

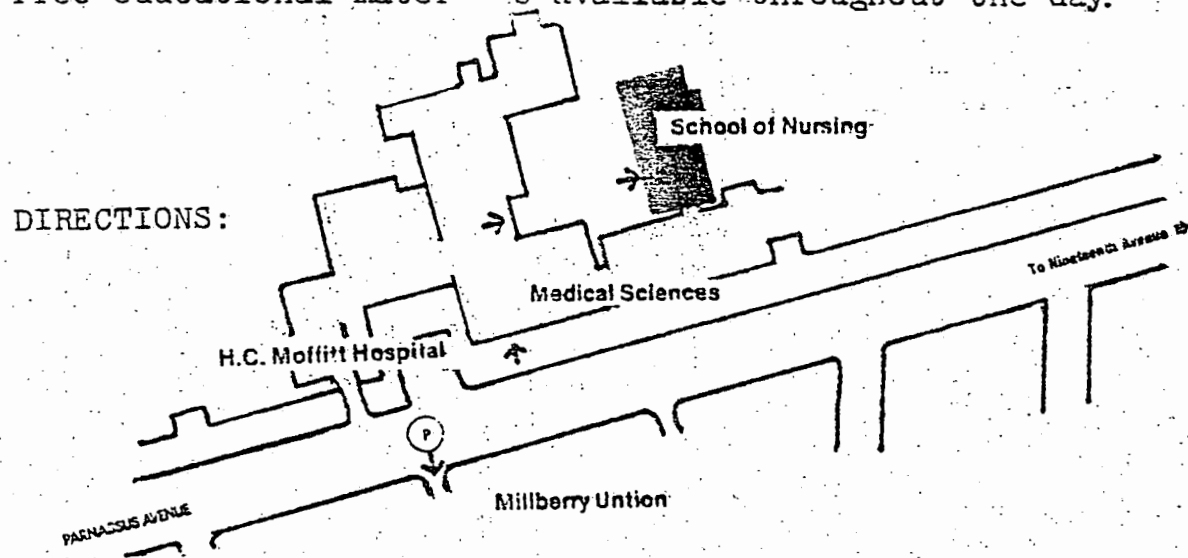
LUNCH (For sale: books for children and adults dealing with illness, uncertainty and death and dying. Bring funds for this unique opportunity.)

5. Students react to their experiences: panel discussion

BREAK

6. Problems and solutions in the classroom: educators meet in small groups to identify needs, problems, solutions
7. Coping with identified problems, resources
8. Emotional survival/closing

Faculty includes: Arthur Albin, M.D., Rita Fahrner, RN, David Knopf, M.S.
 Sondra Barrett, PhD, Mary Watson, B.A. (teacher)
 Free educational materials available throughout the day.



REGISTRATION FORM

NAME _____ SCHOOL _____

ADDRESS _____ POSITION/GRADE _____

REFERRED BY _____

NAME OF CHILD IN CLASS _____ YOUR PHONE _____

CHECK FOR CREDIT (A SHORT EVALUATION WILL BE REQUIRED) 1/2 Unit 6 CEU's (pending)

PLEASE ENCLOSE A CHECK FOR \$20 (THIS COVERS LUNCH) PAYABLE TO: PEDIATRIC ONCOLOGY PARENT HOSTESS COMMITTEE

SEND THIS REGISTRATION TO: DAVID KNOPF, M.S.W.
 UNIVERSITY OF CALIFORNIA, SAN FRANCISCO
 400 PARNASSUS A46P
 SAN FRANCISCO, CA 94142

THE CHILD WITH LIFE THREATENING DISEASE

MPS WORKSHOP

SPRING 1981

Instructors: Mary Lauer, R.N.
Gordon S. Leonard, Ph.D.

General Requirements:

1. Outside readings as assigned.
2. Project: to be written and presented in last two sessions.

Attendance: A maximum of one session may be missed.

February 18, 1981

SESSION I

Topics:

1. Introductions
2. Overview of workshop: the purpose, objectives, and topics.
3. Workshop requirements
4. The Medical Aspects of Childhood Cancer

February 25, 1981

SESSION II

Topics:

1. The Nursing and Practical Aspects of Childhood Cancer
2. Impact of the Treatment Process on Neuropsychological Functioning

March 4, 1981

SESSION III

Topics:

1. Psychological patterns of adjustment in families of children with cancer.
2. Enhancing the functioning and coping abilities within families of children with cancer.

March 11, 1981

SESSION IV

Topics:

1. Communicating with parents of children with life threatening disease.
2. Open discussion with some parents of children with cancer regarding specific parent-teacher-student concerns.
3. Class reaction to parent discussion.

March 18, 1981

SESSION V

Topics:

1. Exploring your own feelings.
2. Defining the teacher's role.
3. Presentation of workshop projects.

March 25, 1981

SESSION VI

Topics:

1. Continuation of workshop project presentations.
2. Discussion of community resources.
3. Collection of written projects.
4. Evaluation of workshop.