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The role of the school counselor in helping chronically ill students

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Abstract

Statistics kept since the passage of the National Cancer Act in 1971 indicate that slow but significant gains in lengthening the life span among many cancer patients have been made. The five-year survival rate for seven of the fourteen cancers in children and adolescents including all leukemias, Wilm's tumor, Hodgkin's disease, and neuroblastomas has increased dramatically. Dr. Edward Beattie Jr., Director of Memorial Sloan-Kettering Hospital in New York City, estimates that half of all cancer patients could now be cured, meaning to live their lives without a recurrence of their cancer, if all the available diagnostic and treatment techniques were used (Brody, 1981). Through proper treatment almost 90 percent of all children and adolescents with acute lymphocytic leukemia and Hodgkin's disease, the two most frequent cancers for that age group, are put into a disease free state known as a remission which becomes permanent in 50-60 percent of all cases. A formidable arsenal of forty chemotherapeutic drugs have been developed, thanks to funds raised by the Leukemia Society, the American Cancer Society, and the National Cancer Institute.

THE ROLE OF THE SCHOOL COUNSELOR IN HELPING CHRONICALLY ILL STUDENTS

A Research Paper
Presented to
the Department of School Administration
and Personnel Services
University of Northern Iowa

In Partial Fulfillment
of the Requirements for the Degree
Master of Arts in Education

Nancy Camp Warren
June 1982

This Research Paper by Nancy Camp Warren

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has been approved as meeting the research paper requirement for the Degree of Master of Arts in Education.

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Dec 13, 1982
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To Bobbie, Elliot, Heather and Sara

This paper is lovingly dedicated to these four beautiful kids--all of whom I have loved and lost as did their parents, friends and relatives. The memory of these courageous, outstanding and wonderful youngsters has inspired me daily as I worked on this assignment. They serve as a reminder that life is truly precious, sweet and fulfilling because they fought so hard to keep it and in losing it, have inspired us all to live life well.

June 25, 1982

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CHAPTER I

Introduction

Statistics kept since the passage of the National Cancer Act in 1971 indicate that slow but significant gains in lengthening the life span among many cancer patients have been made. The five-year survival rate for seven of the fourteen cancers in children and adolescents including all leukemias, Wilm's tumor, Hodgkin's disease, and neuroblastomas has increased dramatically. Dr. Edward Beattie Jr., Director of Memorial Sloan-Kettering Hospital in New York City, estimates that half of all cancer patients could now be cured, meaning to live their lives without a recurrence of their cancer, if all the available diagnostic and treatment techniques were used (Brody, 1981). Through proper treatment almost 90 percent of all children and adolescents with acute lymphocytic leukemia and Hodgkin's disease, the two most frequent cancers for that age group, are put into a disease-free state known as a remission which becomes permanent in 50-60 percent of all cases. A formidable arsenal of forty chemotherapeutic drugs have been developed, thanks to funds raised by the Leukemia Society, the American Cancer Society, and the National Cancer Institute. Current treatments are a combination of these drugs, radiation, and surgery. The cure rates are rising for all malignancies including the previously resistant rhabdomyosarcoma and childhood lymphomas (Yohn, Graff, 1981). Children and adolescents can now have a quality and span of life approaching normal. The chemotherapeutic drugs used in sequence and combination with prophylactic radiation therapy and intrathecal methotrexate require one or more periods of hospitalization, many outpatient visits for maintenance drug administration, and demand an extensive and expert management over a long period of time. These treatment regimens for cancers join other established protocols for previously potentially fatal and debilitating diseases such as cystic fibrosis, diabetes and rheumatoid arthritis that are yielding success, and together they have produced a new group of patients designated as "chronically ill" (McCarthy, 1980). Continuous care must be taken over the years as any relapse indicates less prospect for cure, and a relapse may occur after years of a complete remission (Tiller, 1977).

Nationally the incidence of newly diagnosed childhood and adolescent cancer cases in 1980 was 6,200 and for 1981, 6,000 (Cancer Information Service, 1982). In our own state of Iowa at the University of Iowa Hospitals and Clinics, the Department of Pediatrics over a ten-year period, 1971-1981, has diagnosed and treated from 79-114 new cases each year. There are currently 300-450 active cases of surviving cancer patients seen by the University of Iowa Pediatric Clinic each year. It is well documented that the numbers of the survivors of childhood and adolescent cancers are rising (Strayer, 1982).

Because of the advances in medical technology, students who would have become terminally ill within a short time after diagnosis now return to school for ever increasing time periods, and many will grow up to be adults and live a normal life span. Thus the school counselor should assess his/her attitudes towards these "chronically ill" students and become aware of the special psycho-social problems that these students face during their school years and become prepared to assist them in a variety of ways both in and out of school.

What is the role of the school counselor in helping those students identified as "chronically ill?" This paper proposes to address the question by interviewing "chronically ill" students and their parents through the use of a semi-structured set of questions (see appendix for questions). The eight students interviewed were all asked the questions by the interviewer, though not in a rigid, prescribed, one-two-three order. The semi-structured interview format was chosen because it provided greater flexibility. The interviewer could explain the questions if necessary and assist the student to clarify his responses. Also, the interviewer could observe the student and ask relevant questions to elicit any intense response. Bogdan and Taylor (1975) provide support for the use of the qualitative method of interviewing and conclude the interviewer may rely on the assumption that a student's responses are "true."

In most cases the student, if an adolescent, answered the questions directly, but on some occasions parents also commented on the question or reminded the student of previously expressed attitudes, complaints, or opinions. In the case of Shelly, age 15, who agreed to be interviewed and then refused or in the cases of the elementary students involved, ages 6-8, their parents supplied most of the answers. Information on Elliot, age 8½ at his death in April 1979, was gained from the interviewer's own personal experience as he was the interviewer's son. His story was written by the interviewer as a research assignment for the Death and Dying Seminar at the University of Northern Iowa and his experiences provided the impetus for this paper.

All the students who were interviewed were in remission from their disease; some were still on maintenance therapy, some were in active treatment from a relapse, but all were attending school at the time of the interviews and living at home with their parents. The eight who were interviewed and their diseases were: Gary, age 14, a white male, an acute myelogenous leukemia sufferer; Brian, age 14, a diabetic, white male; Jerry, age 16, a white, male Hodgkin's disease victim; Pam, age 13, a white, female rheumatoid arthritis patient; Wendy, age 6, a white, female acute lymphocytic leukemia case; Heather, age 7, a white, female sufferer from a Wilm's tumor; Sara, age 7, a white, female acute lymphocytic victim; and Jeff, age 6, a white, male with a brain tumor that had also taken his sight. All the interviews were tape recorded with the exceptions of Jeff, who quickly climbed into the interviewer's lap and the tape recorder was forgotten and Jerry, whose interview was done in connection with working with the CISI Quest and the Apple II computer, making taping difficult.

The medical caregivers for a number of these patients were also interviewed (and tape recorded) and were queried for suggestions as to how schools and counselors, especially, could more effectively help these students. Dr. John Justin, pediatrician in Mason City, Iowa, gave his time and discussed his patients, Heather and Sara, at length as well as the parents' support group which he initiated. Dr. F. G. Dannenbring, a pediatrician at the Fort Dodge Medical Center, Fort Dodge, Iowa, cared for the interviewer's son for three years on the University of Iowa's Shared Maintenance Program and was very instrumental in putting the interviewer in touch with his patients: Wendy, Pam, Shelly, Gary, and Jeff. Dr. Raymond Tannous and Dr. C. Thomas Kisker, Associate Professor and Professor of Pediatrics, Department of Hematology-Oncology, University of Iowa Hospitals and Clinics, were helpful in their information. These two and their medical team have cared for all of the students with cancer, including the interviewer's son, that were interviewed, with the exception of Gary, who is cared for out of state. Other members of the oncology team at the University of Iowa interviewed were two oncology nurses: Mary Lou Lindeman and Jean Davison who gave help, suggestions, and literature. Ruth Isaacson, pediatric social worker, also offered suggestions and parallel experiences from her office.

Information from chaplain-counselor Reverend James Brasel, St. Joseph's Mercy Hospital, Mason City, Iowa, dealt primarily with the support group that he and Jana Grady, social worker, led for the parents of cancer patients in the Mason City area, primarily for Dr. Justin's patients.

The literature at the Health Sciences library at the University of Iowa and the University of Northern Iowa library was reviewed for information on students with chronic illnesses, families with chronically ill students, research studies on the social-psychological aspects of being a young chronically ill student, and information on effective counseling strategies and techniques for students with chronic illnesses.

The interviews were conducted from April 1981 to May 1982 and were generally done in the students' homes with three exceptions: Jerry's was done at his high school, where he felt more comfortable; Brian's was done at the interviewer's home, where both mother and son had visited many times; and Shelly's mother was interviewed at the home of Shelly's school counselor, friend of the interviewer. This seemed more comfortable for Shelly's mother because of Shelly's refusal to come along and because of remodeling in her own home. The interviews with the medical caregivers, the social worker, and the chaplain-counselor were done in their offices. The literature was reviewed from April 1981 to June 1982 in Iowa City, Iowa, and in Cedar Falls, Iowa.

Basic Assumptions

The basic assumptions or hypotheses that underlie this proposed delineation of the school counselor's role in assisting chronically ill students are the following:

1. The counselor can aid the student's reentry into school; academically, physically, and psychologically.

2. The counselor can help the student cope more effectively with the socio-psychological aspects of his/her chronic illness.

3. The counselor can assist the student's family, the parents, relatives, and especially the student's siblings also enrolled in school.

4. The counselor can serve as a consultant to the student's teachers on academic, physical and psychological problems and limitations.

5. The counselor can serve as a liaison person between the medical caregivers and the school personnel and work in cooperation with the school nurse.

6. The counselor can assist the student's classmates to cope with someone who is perceived as being different or handicapped and can promote the acceptance of a chronically ill student.

7. The counselor can serve as a consultant to school personnel and the student body on coping with the possibility of the death of a student and also their own mortality through Death Education seminars and group counseling sessions.

8. The counselor can assist and advise the Peer Helping class on involving themselves with chronically ill students so as to assist with their special needs and to provide friendship.

9. The counselor through counseling sessions can help students cope more effectively with their disease and its treatment, even perhaps to affecting the progress of the disease and the effectiveness of the treatment.

Terminology

"Chronically ill" is used in this paper to describe students with a medical condition that requires intensive and expert medical management and aggressive intervention with drugs, radiation, and/or surgery to contain and control it. The disease demands continuous monitoring and maintenance therapy over a number of years, has the potential to be fatal, and is characterized by lengthy periods of normalcy known as "remissions," a circumstance evidenced by no trace of the malady. The examples chosen for this paper were students with the following types of diseases:

1. Acute lymphocytic leukemia (ALL), a cancer of the blood producing organs of the body; i.e., spleen, bone marrow, which affects the white blood cells called lymphocytes, and is characterized by the presence of abnormal cells in excessive numbers and is the most common type of cancer in children ages 3-14.

2. Acute myelogenous leukemia (AML), also a cancer of the blood producing tissues, but affecting the white blood cells known as granulocyes, which are abnormal and appear in excessive numbers, generally affects adolescents ages 12-18, does not respond well to chemotherapy, and has a high fatality rate in young people.

3. Hodgkin's disease, a cancer that affects the lymphatic system, which includes the lymph, lymph vessels, and the lymph nodes and is a very common type of cancer in adolescents ages 12-18, generally responds well to chemotherapy and has a high cure rate.

4. Wilm's tumor, a malignant growth in the kidney which does respond to surgery, radiation, and chemotherapy quite well in most cases but which can metastasize rapidly, systemically, and can then be fatal, which affects young children ages birth to ten.

5. Malignant tumor of the brain, a cancerous growth within the brain, treated by radical, excisive surgery,

radiation, and chemotherapy with blindness a common side effect, has a high fatality rate, can affect all ages.

6. Cystic fibrosis, a disease that affects the mucous membranes of the entire body, characterized by severe lung and stomach lining tissue involvement evidenced by the loss of elasticity and a fibroid composition, caused by a lack of an undetermined enzyme in the system, severely affects the breathing capacity and digestive abilities of the patient, is transmitted genetically and affects children and adolescents from birth to age 18, is treated by chemotherapy, inhalation therapy and has a high fatality rate.

7. Diabetes, a disease in which the ability of the body to use sugar is impaired due to the malfunctioning of the Islets of Langerhans in the pancreas which fail to produce insulin in sufficient quantities to digest sugars, characterized by total systemic involvement, treated by daily injections of insulin and careful monitoring to maintain a balance of sugar intake and insulin to avoid either insulin shock or diabetic coma, affects patients of all ages, but is very serious in juveniles as diabetes is most difficult to regulate and control because of the rapid growth; a great possibility of damage to eyes and kidneys.

8. Rheumatoid arthritis, a chronic disease marked by signs and symptoms of inflammation of the joints, accompanied by marked deformities and general involvement of the entire system, a degenerative disease marked by ever increasing disability, affects all ages and is particularly serious in children and adolescents because of the rapid growth of bones and tissues.

"Relapses" are highly possible in all of these diseases, a condition in which the disease returns in full force after all symptoms have yielded to treatment and no traces of it can be detected. Relapses are emotional as well as medical crises, as each relapse generally signals a chemotherapeutic failure, meaning the offending cells have become resistant to the drugs, making the disease more difficult to treat and control. Thus, each relapse signifies that the possibility of death becomes more real, and the patient must deal with these emotions as well as combating the physical manifestations of the illness.

The medical caregivers stressed over and over again in connection with school attendance "individuation" for chronically ill students, meaning that each student needs to be dealt with as a distinct and separate entity with special and unique circumstances. The treatments, the progress, the problems, and reactions of each student should be known by the school personnel with whom he/she comes in contact. An example of "necessary knowledge" is the post-radiation syndrome, which occurs in leukemia students about six weeks after prophylactic cranial radiation. Extreme somnolence overtakes the student for about a week and the student may seem never to be alert. Any teacher dealing with this student would be convinced that all is hopeless and learning will never occur. Or teachers, if not aware of the facts of the case, would be hard put to understand why parents have kept the child home to sleep for a week. If school personnel don't understand the danger from chicken pox to a student with cancer, a simple childhood disease for most, they will fail to alert the parents of cases in school so the student could be withdrawn and tutored at home for a period of time to avoid catching the disease, which can be fatal to patients on chemotherapy.

CHAPTER II

Review of Literature

Numerous articles and pamphlets have been written addressed to the problems and discouraging aspects of being chronically ill. A number have been concerned with the reentry to school after diagnosis and induction. This is a big hurdle for the chronically ill student. But this reentry is so vital. It signals a return to normal living and provides a sense of the future (Sachs, 1980). Life must continue to be meaningful and rewarding even though lived under extenuating and handicapping conditions. Learning and growth should not be interrupted by disease and its prognosis (Evans, Needle, 1980). Chronically ill students can derive great personal satisfaction from being at school and continuing to learn and achieve scholastically. In order to reenter school support must be gotten from parents, teachers, and the medical team (National Cancer Institute, b, 1980).

A plan for the student to return to school should be made by the student, the parents, school personnel, and if possible, the student's medical team. One person should serve as a liaison for the school, the student's family, and the treatment center. He/she should become informed about the specific type of cancer, the treatment protocol, the potential side effects, effects on the student's appearance, and the upcoming treatment schedule. If there are limitations on the student's activities, these need to be known by all the school personnel. Adolescents in junior high and high school generally know all about their disease and usually would like to tell their classmates directly about it (National Cancer Institute, b, 1980). Usually the teacher tells an elementary class and influences both the adjustment of the student and the classmates and helps the class understand the student's limitation (Greene, 1975). It is necessary to be straightforward and explain the child's illness and answer classmates' specific questions. One teacher simply told the class that the long-absent child now returning had only had a bad cold. When the child returned bald and ten pounds heavier because of steriod therapy, many of the students exhibited great anxiety over catching a cold (Greene, 1975).

The teacher or counselor should discuss with the class how they would like to be treated if they were ill and elicit feelings as to how they feel when they're around someone who is ill. This can provide a springboard to a discussion on how to treat the returning ill student. For adolescents, reports in a science or health class can be assigned on chronic diseases; for example, cancer, and can be given orally so all students will have a basic knowledge of the disease. Supplemental presentations can be given by guest speakers who are knowledgeable in the specific field of the illness, in this illustration an American Cancer Society representative (National Cancer Institute, b, 1980).

The chronically ill student should be treated as normally as possible. He/she should not be singled out for special privileges, should not be overprotected, and should follow the rules and do the classroom work in order to pass. The student needs to feel that he/she has succeeded like everyone else (Greene, 1975). Learning or behavioral problems such as fighting, hostility, or irritability should be referred to the counselor, the student's family, and the medical treatment center (National Cancer Institute, b, 1980).

Tutors may be assigned to newly diagnosed junior and senior high school students immediately while they are still hospitalized and the tutors may stay on the job after the student's return to school. The student may prefer to audit classes at school so as to be with friends and work for credit with his/her tutor, allowing more flexibility around treatment schedules (Sachs, 1980).

All teachers in junior high and high schools need to be kept informed of the ill student's needs, treatment schedules, and medical progress to understand the student's absences. Also contact needs to be maintained by the school with the student during lengthy absences. Each semester the school personnel should meet and the student's status updated and reviewed. The counselor should meet frequently with the student to discuss academic questions and problems and any social and psychological problems the student may be facing. Teachers should be aware of this relationship so as to refer problems or questions to the counselor (National Cancer Institute, b, 1980).

Teachers have difficulties with the reentry of a chronically ill child to school. They generally have many questions but don't always know who to ask for answers. There is some hesitation to talk with parents at times because the parents themselves may be overcome with guilt, anxiety, and limited time, especially if both work. Also, teachers need a sounding board to talk out their own feelings about the child, especially about the prognosis of the disease. The counselor could design a questionnaire to help teachers organize and focus on questions he/she wants to know and problems he/she anticipates. Then the amount of information needed can be more adequately assessed. One of the major questions tends to be, "How do I know when to force the child to participate in activities and when to back off?" (Greene, 1975). Other questions that concern teachers about chronically ill students center on the teaching methods one uses with an ill child/adolescent; the learning skills needed by the child/adolescent; the criteria to evaluate a repeatedly absent child/adolescent (an average of 30 days in a school year); promotion policies; the child's/adolescent's true intellectual abilities; handling the child's/adolescent's emotional difficulties in the classroom; the means to help the student gain social acceptance; measures to use in case of a classroom medical emergency such as bleeding, insulin shock, or breathing disorders; the effect of the home life on the student's illness; and the amount of extra time involved to help the student keep up.

The following suggestions were made to help ease the way in school for chronically ill students:

1. Research to educate school personnel and fellow students.
2. Public information exposure to research results.
3. Comprehensive health programs, K-12, in schools about chronic illnesses.
4. Educational policies concerning chronically ill students, including evaluation, special classes, teacher training specifically on the education of this type of student.
5. Teachers as role models for acceptance of these students.
6. Promotion of peer understanding.
7. Promote student's school attendance and involvement in social activities.
8. Contact the student outside of school.
9. Promote more understanding of students with special needs.
10. Combat prejudice against these students (Chapman, 1980).

School Reentry

There has long been concern among educators about the intellectual capabilities of chronically ill students. These students don't appear as bright because they are absent so much that they fall behind in their school work due to hospitalizations, clinic visits, and recuperation periods. They fail more often in school and get, on the average, poorer grades than their fellow students. There is a belief that the ill child is a "dumb child," based on the belief that once disease invades the body, all of the systems are affected including the brain (Chapman, 1980). There is a special concern about the survivors of cancer that have undergone prophylactic cranial irradiation to prevent central nervous system leukemia (CNS). At the Royal Hospital for Sick Children in Bristol, England, research has been done on the mental capabilities of a group of survivors using the Wechsler Intelligence Scale for Children and the Burt Reading Test. The survivors of childhood leukemia (ALL) scored as well on the measures of language ability as did the controls. They scored below on both quantitative and verbal reasoning tests and in all measures of performance that involved novel and abstract material where speed is critical. For the performance scale IQ tests, the children who had undergone cranial irradiation scored generally lower than the controls. The earlier in life the irradiation, the lower the scores, suggesting that the irradiation affected brain growth and development. All the questions have not been answered here, however. There is no data on the effects of chemotherapy, especially methotrexate and radiation combination, none on the decreased days in school, none on the effect of psychological stress connected with the disease and its treatments, none on the deterioration of the brain due to the disease itself. Answers will not be forthcoming as it is difficult to isolate any of these factors. Age of irradiation certainly seems to be a critical factor, as those irradiated after five years of age appeared less affected than those before five years of age. The effects of irradiation do not appear to be reversed over time as the effects of the chemotherapeutic drugs appear to be. Educators need to be aware that verbal achievements in this study were shown to be generally unimpaired but extra help would be needed in the quantitative areas. These students are deemed medically "successful," as they are ALL survivors. Those undergoing treatment may experience similar or even more serious problems (Eiser, 1978).

A study conducted at the University of Iowa Pediatric Clinic with newly diagnosed pediatric cancer patients showed that on the Wisc-R (Wechsler Scale for Children Revised) 15 out of 38, or 39 percent with ages 6-17, the verbal IQ skills were lower than the performance IQ skills (Stehbens, Ford, Kisker, Clark, Strayer, 1981). All had had vincristine and prednisone, the standard induction drugs, all had received L'asparaginase and intrathecal prophylactic methotrexate, and three had received cranial irradiation. Depression was not considered to be a factor in these scores. Anxiety might be crucial as students with cancer exhibit higher anxiety levels than other children.

Physical Problems

Problems do occur with the physical changes that occur as part of the treatment of chronic illnesses. Alopecia is an effect of chemotherapy and cranial radiation and causes great distress for those who are concerned with physical appearance and body image. If a wig is worn by the student with cancer, classmates may want to peek under it (Greene, 1975).

Steve Bennet, age 15, from a family of football heroes, had his leg amputated from the hip because of osteogenic sarcoma. He also was injected with the very powerful chemotherapeutic drug, adriamycin, and all his hair fell out. This drug, like all anti-cancer drugs, affects all fast-growing cells and does not discriminate between cancer cells and hair cells. He said that it was harder for him to accept the loss of his hair than the loss of his leg, which was replaced by a prosthesis. He got a wig and wore a cap on it and was thrilled when his hair grew back in, even though it was a different color and curly (Pendleton, 1980).

Adolescent girls seem hardest hit by the realities of their cancers and their effect on their attractiveness. They fear the loss of beauty, loss of hair, and loss of reproductive potential. Adolescent guys seem at first to be better controlled, but later in treatment seem to have more difficulties with hair loss and suffer more breakdowns and have more despair (Evans, Needle, 1980). Adolescents who feel physically unattractive may anticipate rejection and avoid physical contact. They feel with body disfigurement or treatment or being bald that they are not "sexy." These students have to work through feelings about their changed body image. Taking up physical activities--sports, dancing, judo, or yoga--will improve their sense of being in touch with their bodies. A new challenging activity like skiing for an amputee, for example, gives one a whole new feeling of self-worth. Acquiring new interests and talents strengthens one's personal self-image (Hartman, 1980).

Radiation dermatitis is a condition that results from radiation therapy and is characterized by brown, peeling skin. Generally, adolescents undergoing radiation are discouraged by the medical team from outdoor swimming or sunbathing for the duration. But some cease to swim even indoors because of their skin's appearance. Also, the marks for the radiation sites are marked on the body in indelible ink, causing embarrassment to teens. There are some adolescents who would choose to die rather than be disfigured (Moore, Holton, Marten, 1969).

Classmates can be extremely cruel to children suffering the effects of chemotherapy. Prednisone, a steroid, causes enormous weight gain in patients because it stimulates the appetite along with killing cancer cells. It also causes a pseudo-Cushing's Syndrome effect, better known as "chipmunk cheeks" or facial fullness. It also causes moodiness and great swings in moods from easily tearful to easily cheerful. The student is always hungry and eats enormous amounts of food numerous times a day (Schweers, Farnes, Forman, 1977), (Sachs, 1980).

Mikie Sherman's daughter, Elizabeth, suffered much cruelty at the hands of her classmates when later in her illness of leukemia her hair was lost, lots of weight was gained, and her physical energy was low. She was taunted daily on the playground with "fat face" and "baldy." She never told her teacher about the teasing, being too proud to do so, and didn't complain about being excluded from the playground games. She found it very hard to form friendships and was socially isolated both in and out of the classroom. Her mother picked her up after school to avoid an unpleasant bus ride and talked directly to the parents of several children who were extremely cruel (Sherman, 1979).

In a research study done in England, some retardation of growth was suspected in survivors of leukemia after intensive chemotherapy and cranial and spinal radiation, but it appeared that for girls the chance for normal physical and sexual development at puberty was 80 percent and for boys an even better chance. If testicular infiltration had occurred in the course of the disease, it had been necessary to radiate the area and sterility was the result. Few children have been born to ALL survivors but studies show no excess of birth defects (British Medical Journal, 1978). In a follow-up study Swift (1978) evaluated the growth hormonal states of 14 children now aged 7-15 after chemotherapy for ALL and found no growth problems. He further confirmed that these patients were passing through puberty with no problems.

Chronically ill students who have physical handicaps such as a leg prosthesis may have difficulties reentering school because of architectural barriers. Because of 94-142, a public law to help the handicapped, these difficulties should be fewer and modifications should have been made in older buildings to provide easier access for those students with amputations or limited energy. A plan should be structured to provide for easy entry desks for a child or adolescent who has a leg prosthesis or to allow the student on crutches to leave class five minutes early for lunch or his/her next class and have some help with his/her books and his/her lunch tray.

Special transportation may also be needed for such students, especially during icy and/or snowy weather. The hardest to convince of this are the students in need, as they want to do as they've always done and not appear different. Getting on and off school buses will be a problem for these students and a way to help should be provided (Sachs, 1980).

Psychological Problems

The chronically ill student has many psychological concerns and problems in dealing with his/her medical condition in and out of the school setting. A study of personality profiles done with chronically ill children showed a greater anxiety level in these children than in healthy children (Burns, Zweig, 1980). These children saw themselves as being more friendly than the healthy child, perhaps in compensation for their feelings of alienation. The chronically ill child used denial to allay anxiety and keep functioning and in every way attempted to be as much like other children as possible. In a study on the impact of ALL on the family, it was found that the ill child must be reassured that lies will not be told to him/her and that he/she will not be deserted physically or emotionally. The ill child needed to know that he/she can voice aloud his/her feeling of sadness, fear, helplessness, loss, and anxiety (Binger, Ablin, Feuerstein, Kushner, Zoger, Mikkelsen, 1969).

Chronically ill students deal with prejudice in the classroom by "acting out," resorting to aggressive verbal and physical behavior, to gain the attention they feel they haven't received through normal methods because of repeated absences and being viewed as different (Chapman, 1980).

In a study done in England using interviews with survivors of leukemia (McCarthy, 1980), 26 of the 64 subjects attended school as all were under the age of 15. Of the 26, 16 were making good academic progress, but six had serious evidence of difficulties such as a lack of self-confidence, not playing well with other children, and slower academic progress. These students showed high levels of anxiety, depression, aggression, and psychosomatic illnesses such as headaches, tiredness, and body pains (McCarthy, 1980).

Many chronically ill students have a great deal of anxiety about falling behind the class in their school work or not passing, even in the early stages when they must be hospitalized. These fears may bring about a condition of refusal to attend school, or school phobia, if reassurance is not promptly given (Sachs, 1980).

Problems with self-esteem began for some students with cancer (Peck, 1979) in elementary school when their teachers indicated to them that education was unimportant for them since they had no future anyway. Two became dropouts and one had to take extra schooling in senior high school.

The possibility of death must be discussed with chronically ill adolescents as this is the group hardest hit by having a potentially fatal disease. It is usually easier for students to talk about painful topics with someone outside their family rather than their parents as the adolescents feared upsetting their parents by presenting their own pain and apprehensions. They were protective of their families and feared being down emotionally. But the adolescents needed to have an emotional catharsis. These adolescents needed to be assured of someone to talk with and that this person will be available constantly. This person must invest completely in these students and must realize that if the case turns terminal, lots of hurt and grief will result to the listener, but to do only a half-way job would deprive the student of help at a time of his/her greatest need (Evans, Needle, 1980).

All chronically ill students live in fear of a relapse and repetition of treatments. All the emotional energy used previously to keep up in school must now be used to cope with their illness. In addition, they become more dependent on their parents at a time when they are developmentally moving towards independence; they see friends withdraw who now view them as differnt, and they themselves may feel like regressing to a younger-age behavior or becoming belligerent (National Cancer Institute, b, 1980).

David, age 14, a chronically ill student, was constantly exhausted from his illness. He became uncontrollable in his behavior, and his counselor found that David feared he was not masculine, that he had had several homosexual encounters. He felt himself to be weak and equated his weaknesses with being feminine. He feared that being feminine meant that he was a homosexual (Haynes, 1977).

Adolescents who are chronically ill face basically four catagories of psychological problems: the alteration of self-concept, the alteration of body image, difficulties in interpersonal relationships, and interference with future plans (Moore, 1969). Being different in the adolescent age is like being doomed. The major concern of this age is not usually, "Will I die?" but "How will my friends react?" How they do react usually gives the ill student a feeling of inferiority and a loss of self-esteem. Many would like to keep their disease a secret but it is difficult with a bald head, a false leg, or extreme fatigue. Teachers may feel that the ill students are seeking extra attention or avoiding work, that they are lazy. Teachers may complain to both student and parents, making the student feel more inadequate and unacceptable. Denial of the illness is the most frequently used coping mechanism by adolescents, especially among friends. He/she is usually unwilling to tell friends about the disease or discuss it and may pursue activities that are harmful. Physicians feel a certain amount of denial is valid in order to function on a par with peers, but they are concerned about the over-compensating student who may study too hard in order to outdo peers. The risks of harm may be worthwhile, however, if they have success and their self-concept is strengthened. But if new signs and symptoms of recurring disease are ignored and untreated in this denial process or an injury results, the ill student may be in serious medical trouble before he/she will admit to problems. Another coping mechanism is intellectualization, used by students to handle the anxiety about their disease. They focus on the clinical aspects of their disease, avidly read about it, do term papers and reports on it in order to separate their thoughts from their feelings.

Anger at their medical condition is an ongoing circumstance with chronically ill adolescents and it may be projected onto parents, medical caregivers, teachers, counselors--those adults who try to help. This anger is rarely taken out on friends as the risk of loss is too great (Moore, 1969). Unexpressed anger or fears uncoped with by the adolescent leads to depression. Chronically ill adolescents should always be given the correct facts about their disease at all times so as not to panic them or to raise false hopes. The death of a friend from treatment who has the same disease or a similar one will plunge the student into a depression and cause renewed fears about their own mortality. A relapse and the necessity for reinduction to achieve another remission will also cause depression. These adolescents must have time to express their feelings about these events, cope with the stress, and remobilize their inner strengths to go onward (Moore, 1969). If amputation of an arm or a leg has to happen, the students go through a period of mourning for the lost limb and conclude that they are ugly. They then may put up a front of healthy adjustment but stand in need of an even greater amount of emotional support to finally adjust.

Interpersonal relations are difficult for these students with adults because they feel so dependent and are trying to establish their independence. They view themselves as weak and helpless. These students suffer when thoughtless remarks are directed at them by their peers and interactions with the opposite sex may never be attempted if the student feels that he/she will be the butt of jokes. The friends of the ill student generally feel threatened by their friend's illness. They fear this or something similar may happen to them and they don't know how to react to their friend's disfigurement or weakness. The ill student may be so involved in his/her concerns and problems that he/she can't see the problems his/her friends are having and realize that he/she must make an effort to "reeducate" friends and peers about illness itself and also rebuild and reestablish relationships anew (Moore, 1969).

The ill students have had experiences which help them to renew their lives and reestablish friendships (Seidl, Atlshuler, 1979). They have been involved in a complex health care system; have had long-term relationships with a health care team to which they've grown very close; they've had lots of excellent role models of caring, helpful people on the medical team; they are empathic; have an extensive medical vocabulary; can interact well with adults; have learned some assertive skills; have all sorts of coping mechanisms, particularly for pain and separation; and have generally good communication skills, usually better than their classmates. Assistance should be given to these students to increase their skills in decision making, resolution of conflicts, coping with stress, anger, pain, sadness, and unreasonable demands. They need to practice refining of their assertiveness skills, social skills, and expression of feelings. They need to be treated as sexually developing persons and have their privacy protected. They need to have a chance to explore questions that they have about differences between their situation and what is normal for their peers. A great loss of self-esteem results when chronically ill students may have to face the fact that while they may be able to have a normal sex life, they can never become parents; for example, a cystic fibrosis student rendered sterile by drugs.

O'Malley's (1979) findings in a study on the psychological profiles of childhood cancer survivors found 59 percent have adjustment problems and that 12 percent are markedly impaired in their coping skills in adult life. There is some question if the cause was totally the cancer experience. Those who used denial as a coping mechanism and made plans for the future had fewer adjustment problems.

A study of 250 cancer patients (LeShan and Worthington, 1956) evaluated their personalities against a control group of 150 disease-free people. Using a projective instrument validated on 12,000 disease-free persons called the Worthington Personal History, the study revealed four characteristics unique to cancer patients: a) the loss of a significant other and no replacement, b) difficulties in the expression of hostile feelings and a benign facade, c) low self-esteem, and d) difficulties with parental relationships. These characteristics are all very stressful situations. Stress has been shown to be an important factor in the development of cancer growth because stress factors can affect the immune system and foster abnormal cell growth.

Methods that raise a patient's stress tolerance level while decreasing stress may be able to affect the central nervous system and enhance the operation of the immune system. Stress reduction may be accomplished by meditation, self-hypnosis, and autogenic training. Simonton and Simonton have designed a treatment approach that helps patients identify the attitudes and beliefs that have caused life to lose its meaning for them and to alter those beliefs. Counseling could become a weapon in the arsenal of cancer therapy (Pusateri-Vlack, Moracco, 1981).

The social aspects of a chronically ill student's life are a source of concern to the student and to his/her family. Social isolation of such a child involves an "approach-avoidance" reaction with the people the child comes in contact with. People naturally feel concern and sympathy for an ill child, and if the child and his/her family are approached with love, understanding, and immense tactfulness, all will benefit. If pity or displays of concern that are overwhelming are shown to the child and to his/her family, damage results: The ill child is seen as threatening to families with children--this could happen to their child!! Some people don't want to get involved with someone who might die as it would be too upsetting to them and their children. Illness is seen as an unpleasant deviance from the All-American focus on health and fitness. Those who are ill must be at fault (Sherman, 1979). The ill child is perceived as inferior. So the ill child is not included in activities at school or in the neighborhood, "out of sight, out of mind." Absenteeism at school makes social acceptance less, which lowers self-esteem, and lowered self-esteem creates more absenteeism. An asthmatic child had an attack in front of her whole class, withdrew into herself, and was gone from school for ten school days (Chapman, 1980).

Changes in the manner of bringing up their children were made in one-half the parents in a study in England (McCarthy, 1980). These parents said that they "spoiled" their ill child by giving him/her more toys, more sweets, and more outings. They felt that they were more lenient in discipline than previously, but felt they couldn't use physical punishment on them as they would feel terribly guilty.

Social isolation is a major problem for chronically ill adolescents. Physical limitations can keep them out of sports and other school activities. Teasing can cause withdrawal from activities and even from school (National Cancer Institute, b, 1980). Ill students need to develop interests, hobbies, and even jobs that are worth sharing and discussing with their peers.

These ill students must be physically with their peers. If they aren't mobile by themselves, efforts must be made to place them where the action is. If they can't participate in sports events, possibly they can sell tickets, be at the food concession stand, or do the announcing so that they are visible in the community. Making the ill student as mobile as possible should be a big priority. Friends can be taught to get the ill student in and out of cars with his/her wheelchair. Driver's education is of tremendous value to ill teenagers and arrangements can be made for a hand controlled car if need be.

Changes of scene help overcome rebellion and depression, and guides to worldwide treatment facilities are available for families who wish to travel but don't do so for fear of accidents or relapses.

Ill teenagers feel that they have few dating opportunities and are not usually optimistic about their chances. Efforts should be made to match boy/girl patients at treatment centers and at school so they can explore this type of relationship. It is a lift to the self-esteem to find someone who likes them, shares their interests and concerns, and understands their problems.

Chronically ill adolescents need to work to be as independent as possible, to manage appointments for treatment, to manage homework assignments, and to do as much as possible for themselves. Ill adolescents need also to look for ways that they may make a contribution to their community, such as volunteer work at hospitals, libraries, in schools, in churches--perhaps as a Sunday school teacher, in camps as a counselor, or within their own school as a peer helper. Some of these volunteer activities might lead to jobs for them and perhaps careers, particularly within the health professions (Seidl and Atlshuler, 1979).

Don Linville of San Diego, California, had Hodgkin's disease 18 years ago and was cured by radiation treatments. He has suffered with hepatitis and had a near fatal stroke. He is employed by the Control Data Corporation in their program to give disabled people an alternative to disability compensation. He works as a computer programmer, full time, at a computer terminal set up in his home and connected to the company headquarters in Minneapolis, Minnesota. He has been off disability for a year and feels really good about himself (The Messenger, 1982).

Effects on the Family

The chronically ill student and his/her disease has an impact on the whole family, and the toughest blow is the diagnosis. Acceptance comes, the parents turn to each other for support, and the resolution begins to meet all the special needs of the ill child/adolescent and continue living (Binger, 1969).

A study to determine the effect of the illness on family life (Fryman, 1980) found that where the mother accurately perceived the severity of the illness, family stability was preserved. Where the mother distorted the seriousness of the disease, feeling that the child/adolescent was sicker than he/she was in reality, the ill child/adolscent and the family had greater psycho-social difficulties in adapting.

The siblings of the ill child/adolescent often have great difficulties in coping with their brother's or sister's illness (Binger, 1969). The problems encountered were severe enuresis, headaches, school phobia, poor school performances, depression, severe separation anxiety, and persistent abdominal pains. Siblings complained that their parents were totally preoccupied with the ill child/adolescent.

They felt guilt and fear that they, too, might suffer a similar and possibly fatal illness. They felt they were being rejected in favor of the ill child/adolescent.

Within the families of an ill child/adolescent, the problems of the siblings were frequently minimized, denied, or ignored, which reflected the inability of the families to handle any more stress without strain or further adverse effects. The denial of the sibling's problems was an attempt to maintain family equilibrium (Tiller, 1977).

CHAPTER III

Interviews With Medical Caregivers

Communication

The interviews with the medical caregivers elicited many suggestions for schools. According to Dr. Tannous, communication is vital between the school and the medical team. Parents can inform the school on the general aspects of the student's medical condition, but if there are specific questions such as diminished intellectual capacities because of radiation, or problems with a student's attention span possibly traceable to powerful drugs such as prednisone or adriamycin which affect blood pressure and cardiac functions, the medical team should be consulted. A particularly heavy treatment schedule may absent the student from school for a long time, and the school may wish to check with the medical team for realistic expectations as to the student's return, make-up work, and academic progress. A condition known as post-radiation syndrome needs to be understood by teachers as this affects the mental capabilities in an extreme way. Dr. Tannous repeated several times that in the course of treatment and disease management many things are problematic and need to be evaluated and reevaluated as the student progresses through school. Dr. Kisker spoke of an ongoing research project at the University of Iowa to measure the effects of cranial and spinal radiation on students. Dr. Justin mentioned that vincristine and methotrexate, two powerful anti-cancer drugs, have been implicated in causing learning disabilities. Dr. Kisker and Dr. Dannenbring felt strongly that it was acceptable to them if a liaison person from the student's school called regularly to get an update on the student's medical progress and also shared information on his/her school progress, both problems encountered and positive things that were occurring. Dr. Dannenbring, as a primary care physician in the University of Iowa Shared Maintenance Program as is Dr. Justin, felt keenly that he could and would take the time necessary to talk to schools in a conference setting with faculty, as he saw great benefit to his patients.

Dr. Tannous and Dr. Kisker felt that communication within the school about the ill students should be handled by a liaison person, particularly as the student reenters school after diagnosis and induction. Dr. Kisker felt that all the school personnel and particularly the student's teachers should be informed and have a chance to ask questions and then should prepare the ill student's classmates for his/her return. Dr. Tannous felt strongly that the student should be present when his/her classmates are told about the disease so that the ill student knows exactly what was said about him/her and would have a chance to answer questions if he/she felt like it, could openly talk about it and get any misconceptions cleared up right away. Dr. Tannous felt this method would involve the ill student as an information source and would eliminate confusion as to what was said about the ill student. The student would not have a "left out" feeling upon his/her return, especially if another student said to him/her, "We talked about you in science class all hour yesterday because we knew you were coming back today."

Individuation

Dr. Justin and Dr. Dannenbring both made a plea for individuation of the school's programs for these chronically ill students. Dr. Justin felt that the school should have a full case history on file on each of these students and all school personnel in contact with the student should be cognizant of his/her case. He suggested also that school personnel might want to attend American Cancer Society presentations to become more aware of the aspects of cancer in general. Dr. Dannenbring was concerned that allowances be made for ill students in Physical Education classes and spoke of Pam, his arthritis patient. He felt allowances should also be made for absences on maintenance therapy days and the teachers should understand that nausea and vomiting play a part in students' failure to return to school after their injection. These visits to a physician's office are not like a routine check up. One or more powerful drugs has been injected into the blood stream of the patient, and in addition to concern over the possible toxicity to the patient's system, there is always a further concern of an anaphylactic reaction to a drug, an extreme allergic response that causes death in a matter of seconds if not reversed with adrenalin. Each of the drugs has side effects that will affect to some degree a student's school performance, particularly the day or two after treatment. Mary Lou Lindner, R.N., stated that teen-age males have the greatest difficulty in accepting treatment for cancer. They are very embarrassed about throwing up from the drugs. They simply don't talk about their disease and are really uptight about their loss of physical attractiveness and body image.

Precautions

Dr. Dannenbring stressed that school personnel should be particularly on the alert for a chicken pox outbreak among elementary students and immediately inform any students on chemotherapy. The immune system's reaction of these students is very low and a simple childhood disease like chicken pox, which is a virus, has the power to raise havoc and to be fatal. Measles are less serious as all students are now required to be vaccinated before entering school and chronically ill students have been vaccinated like everyone else and are protected.

Dr. Tannous cautioned against contact sports for cancer patients, such as wrestling and football, because of the danger of bruising and bleeding due to low platelets from the chemotherapy, particularly massive internal bleeding.

Normalcy

Dr. Tannous stressed vigorously that normalcy in the lives of the chronically ill student is the goal. He urged that the idea be gotten across that when such a student is in school, he/she is considered normal and well, he/she is not contagious, generally is in remission, and should be treated as nearly like any other student as possible. The medical condition is not an incapacitating one that would keep the student home and out of the mainstream. Dr. Dannenbring echoed the plea for normalcy and school attendance but did indicate that he felt it was wrong for the school to insist that the student attend school if the student's condition begins to deteriorate, the prognosis is poor, or the parents and student are firmly against it. He spoke of Julie, age 15, who died in 1975 of acute myelogenous leukemia. She determined with her parents and the medical team after achieving a second remission after a relapse that her prognosis was poor, and while she felt and was well enough to attend school, she chose not to but stayed home to enjoy what would be her last spring and spent it horseback riding daily. The school called her parents and insisted that she be in classes, precipitating angry feelings on all sides.

The emphasis for each student, Dr. Dannenbring maintained, had to be on the quality of life, not the quantity of years.

Ruth Isaacson, pediatric social worker, stated that for most children and adolescents, the greatest happiness is to be at school with friends and not to be set apart in any way. But teachers need to realize that the student is in a battle for his/her very existence and this takes a real effort. Teachers also need to work through their fears of having a very fragile looking child or adolescent in the classroom. And the child or adolescent needs to work through any guilt feelings they may have about their condition, that they are not to blame for their illness.

CHAPTER IV

Interviews of Chronically Ill Students and Parents

Diagnosis

The first area of concern faced by all the students interviewed was the diagnosis; understanding what it was and the implications for them. For the younger students the early concerns were centered on the treatment regimen; i.e., "Will it hurt? Will it make me sick?" The adolescents' concerns focused on "How serious is it?" "Will I die?"

This phase of shock takes place generally at a hospital or clinic and is usually discussed and agonized over with the student's family, relatives, and friends.

School Reentry and Physical Problems

The first totally school-related concern is entry or reentry to school after the diagnosis and the first aggressive phase of treatment is finished and a remission is achieved. Elliot, diagnosed at age 5½, entered kindergarten that fall after a summer of chemotherapy and radiation with more physical problems than a regular kindergartener might face. A remission had been achieved and, while not totally bald, his hair was very thin and he had a low energy level. He never wore a wig and finally reached a point that he didn't care about his baldness.

He seemed to respond well to school on a half-day basis and was well accepted by both an empathic teacher and fellow students and seemed to progress through kindergarten quite well until he suffered an episode of methotrexate toxicity in April of that year when he withdrew from school to recover. His reentry the following fall was satisfactory and he attended until Christmas, when he suffered a bone marrow relapse. He could not keep up physically on the playground and classroom participation also was becoming difficult. He vowed he would not return until his hair grew back, but he would have returned if his father had felt he was physically and psychologically comfortable. He was tutored by his grandmother. He did not return to school that year but would have returned in the fall if spinal radiation had not been required in Iowa City, where he studied with the hospital teacher.

Heather had attended one day of kindergarten when she was diagnosed and did not attend school until the next year in first grade. She studied with the hospital teacher and an Area Education Agency (AEA) tutor and when she entered school she was bald, pale, and had little energy. She attended school for all of first grade and was well received by classmates and teachers and progressed quite well. She expressed anger many times that she could not keep up with her classmates physically, but she tried to do everything that they did.

Wendy reentered school in mid-year after being gone for chemotherapy and radiation, and she was bald. She wore a wig to school and felt no one would have known she was bald except that her best friend told everyone and some kids then teased her about it. Her own hair grew back much darker and more curly and she seemed to be able to keep up physically and mentally, finishing kindergarten and first grade.

Sara went back to school after being diagnosed in March 1979, following several weeks of treatment involving chemotherapy and radiation, totally bald. She reported that some boys teased her and later, after being on prednisone and gaining lots of weight in the face, she was called "fat face." Sara accepted her baldness very philosophically, and she was bald through much of her 2½ years of treatment, though midway her hair grew back in and was very curly and a beautiful shade of red like her mother's. Her mother reported that Sara was the most feminine of her daughters and took great pride in her long blonde hair, which had never been cut. Sara never wore a wig and rarely a scarf when she was bald, just accepted it all. She progressed well in school academically, seemed to have a high energy level most of the time, and attended school almost constantly in the 2½ years of the disease. Her teachers and classmates were in large majority accepting, and she felt good about attending school.

Jeff attended school as a kindergartener, totally blind, and bald because of a brain tumor diagnosed the previous July and the surgery and radiation necessary to treat it.

His school administration made arrangements for Jeff to have a Braille tutor through an Area Education Agency and his teacher included him in the regular activities of the class, including physical education. Jeff had had regular maintenance therapy through the year. He had a very pale, thin appearance and low energy but seemed to be always interested in school and activities of classmates and family. Jeff will go to a school for the blind at the end of his kindergarten year in May and will board there as well. He will visit at home after he adjusts to the school but will stay at school most of the time.

Shelly was diagnosed at birth as suffering from cystic fibrosis and entered school with the disease. During her elementary years the disease was in remission and she progressed at an acceptable rate. Upon reaching junior high and seventh grade, the disease relapsed and she has had difficulties with the school work and physical education from being absent so much for treatment. Her mother reported numerous incidents of physical distress at school, notably in physical education.

Brian was diagnosed as a fifth grader with diabetes and he was able to return to school fairly quickly. He is designated as a "brittle" diabetic, which means that his insulin dosage is very hard to regulate and he must constantly monitor his physical cues to avoid insulin shock. He has no limitations on sports participation and is out for football and wrestling and plays baseball in summer in an American Legion Babe Ruth League. He lifts weights regularly at a local fitness club and monitors his insulin level constantly. He gives himself one shot of insulin in the morning and receives one from his mother every night. He has had one serious incident of insulin shock at his grandfather's house last summer in which he simply walked drunken-like across the lawn accompanied by a friend who did not realize what was happening until Brian walked right through a neighbor's large flower bed oblivious to his surroundings. The neighbor came roaring out of his house yelling obscenities at Brian. His friend ran into the house for Brian's mother who quickly assessed the situation, gave him gluctose, and felt relief because it had not happened at school as this is a constant fear, particularly when he is participating in sports. Brian also has to eat regularly, eat nourishing foods, and eat on time. When assembly programs at school run late before lunch or athletic trips or games are overlong for one reason or another, Brian runs the risk of insulin shock.

Jerry returned to school also in mid-year after diagnosis in junior high school, not totally bald, but weakened by the chemotherapy, low in energy, pale, and listless. His progress through school has been on time and normal and as a senior next year, he will graduate with his class. He has been in total remission with no relapses and while he is barred from contact sports such as football, he plays baseball and participates regularly in physical education classes. He seems to have friends and seems well accepted, although he is harrassed for his misshapen chin, a result of surgery.

Gary was diagnosed as a fourth grader in early summer and returned to school in the fall, bald, weak, and pale. His treatment has been successful as he went quickly into remission, has had no relapses, and has now been off maintenance drugs for more than a year. This particular type of leukemia is very difficult to treat and is generally fatal. Many adolescents don't even go into remission.

Gary must be gone for checkups regularly, however, and this has caused some problems with make-up work. From time to time he is absent from school to help his mother with his father at home and on trips out of state to be treated. His father was totally disabled in an accident at work in 1976 and has lain bedfast and incoherent since that time. He requires constant care and the family does this themselves. Gary's main physical problem now seems to be a pre-ulcer or possibly an ulcer condition, the diagnosis had not been made at the time of the interview, caused by the family's financial difficulties and his concern for his father. He has finished eighth grade at the time of the interview and will go to a larger parochial school in the ninth grade next fall where his medical case will not be known and his periodic absences will be questioned. He was apprehensive about this.

Pam was 3½ when diagnosed with rheumatoid arthritis and entered school with this medical condition in remission but under treatment at the Mayo Clinic in Rochester. Pam has constant joint pain and must take six to eight aspirin a day for it and sometimes more. She suffers from ringing in the ears because of all the aspirin and periodically goes to the Mayo Clinic for the gold injections which are critical for her continued remission. There are times when she finds it difficult to support her weight, and she remembers her 10th summer which she spent on the couch in the house. She has restrictions on activities, no bike riding or rope jumping because of the stress on the joints, limited participation in gym class, and sports participation in junior high are forbidden. She remembers an incident of tripping and falling in math class as she went to the blackboard and felt terribly embarrassed by the class's laughter and the teacher's remark. She is aware of walking clumsily down the halls and of her somewhat misshapen fingers and wrists and feels they are very noticeable. She will be entering a large parochial high school in the fall and has misgivings about teachers and classmates understanding and accepting her condition. She recalls having difficulties working in the school kitchen handing out milk. At that time she was wearing white wrist braces to keep her "spindle fingers" straight and to support her wrists. The chief cook in the kitchen said she could not hand out the milk while wearing the braces. If she persisted in wearing the braces, she couldn't work in the kitchen. Intervention by the principal and a shift to punching tickets saved her job.

Psychological Problems

A common feeling among all the interviewees was one of anger and resentment at having this disease.

The question, "Why me?" was generally expressed by the adolescents and most notably by Pam, who felt life was very difficult and who exhibited symptoms of depression at the restrictions and limitations caused by the disease. She reported angry outbursts at her family, at some teachers, and at classmates because of her feelings of distress. Her parents concurred with this assessment and had encouraged her to talk with them or her teachers or her counselor at school. She did not feel comfortable with any of these situations.

Gary did not openly express anger and resentment about his condition, but seemed very concerned about his stomach problems and his father's total disability. He knew that a relapse in his disease was still quite possible as he was only one year out of treatment with four to go before a cure would be called.

Heather and Elliot exhibited depression and anger, particularly at the treatment phases they went through. Elliot once angrily expressed dismay at the Jerry Lewis Muscular Dystrophy telethon when he was told that its purpose was to raise funds to find a cure for MD. "Why don't they have a telethon and find a cure for my leukemia and quick!"

Jerry exhibits a semi-tough exterior at school and according to his teachers is something of a discipline problem in classes and in the halls. He admits that he gets angry about a lot of things and that he has difficulty expressing anger. He has chosen to take the Peer Helping class next year at his high school, hoping to learn about himself and his feelings and to help fellow classmates.

Brian expresses his anger at the restrictions imposed by his diabetes by not always following the dietary rules as laid down by his mother or by not eating what she considers sufficiently nourishing foods for meals or snacks when left on his own with no direct adult supervision. He resents any rules that make him "different" from his friends such as restrictions on junk foods. He expressed resentment at changes in the treatment and changes in his insulin regimen which are necessary now as he is growing so fast.

Sara's expressions of anger were always to God, expressed in poems, conversation, and nightly prayers, "Lord, take away this leukemia. It bothers me!" She also expressed it by whining about things and being irritable at home and at school, especially on days when she wasn't feeling well.

Shelly, according to her mother and her school counselor, daily expressed her anger about her condition. She regularly exhibited hostile behavior at school and at home and has become something of a discipline problem both places. She had agreed to the interview on two different occasions and had backed out. On the third, her mother pleaded with her to come and she refused and would not consider a fourth appointment. Part of the refusal had to do with the location. She was not comfortable at her own home because of remodeling. She was not comfortable at her school counselor's home either, nor with a change to the Fort Dodge Medical Center offices of Dr. Dannenbring. Her mother felt that anything which differentiated her from her classmates really angered Shelly, and cystic fibrosis is a differentiation.

Elliot had the only serious case of school phobia among all the students interviewed. After his bone marrow relapse at Christmas in first grade, he showed a definite aversion to returning to school in

February when he was declared in remission and able to return. He returned for the Valentine's Day party that year, but would not willingly say he wanted to return. His classroom situation was difficult, being in an old building six miles away by school bus, on the third floor, on the north side of a renowned cold building with a very rigid teacher who did not like to handle a lot of special problems. It did not help Elliot's mental state that his parents could not agree on his return to school and fought daily about it. His father felt his return to school would take his life by putting undue stress on him physically and mentally. His mother felt that the quality of life was important and that a child's life focused on school and his fellow classmates and that he should go at least a half-day as he was in remission and appeared quite well. No one from his school called or appeared concerned about his absences or even his health. He seemed to be forgotten by the school personnel. The decision was finally made to keep him home and have him tutored by his grandmother, an elementary school teacher, and use materials from school. He finished first grade in this fashion and also studied with the hospital teacher when he was required to be in Iowa City. He never returned to school. He seemed perfectly content with these arrangements and grumbled rarely over his school work with his grandmother.

Feelings About Death

Gary expressed the feeling that he thought a lot at first about dying and that his disease could be fatal. He did feel comfortable talking to his priest-counselor about it at school and worked through some of his fears about it. His particular case has amazed all his medical caregivers and he does not concern himself with an early death anymore.

Jerry was assured from his initial diagnosis that his case was quite treatable and that the medical team felt that they could put it into a long remission and so he felt little concern about losing his life. He felt that he could talk very comfortably with his counselor about death and dying if it became an issue for him.

Pam did not express fears about dying, only anger and resentment at "not being able to do stuff" and "becoming more disabled." She clearly didn't want to talk about it.

Shelly had expressed fears about dying, as her disease was becoming progressively worse, her mother reported. She had been hospitalized twice in the last month and continued to have trouble breathing. Any physical exertion seemed to be a major effort prior to being in the hospital, and it was felt additional treatments might be in the offing.

For Brian, dying is clearly not an issue at this time, but he is aware that diabetes can become seriously debilitating and that he could go blind from it and also have serious kidney problems that could be fatal.

Wendy is not aware that death is a possibility for her as her parents at this stage have not discussed it with her. She is currently in remission and doing well, so her parents feel the issue is not a viable one at this time. She is quite young to have an understanding of what it might mean for her, her parents feel. The family will discuss it when and if the need arises.

The summer after he was diagnosed, Elliot learned that people die from leukemia from a newscast that carried a story about a girl in Florida who had been receiving chemotherapy, but when her hair began to fall out, her parents took her out of the hospital and out of the treatment protocol. The newscaster mentioned that the medical team had said she could die without the treatments. Elliot stated, "That's what I have--leukemia. Will I die from it?" It was necessary to have a discussion right then and there and to explain to him that he could die, that the disease was very serious, and that the treatments could stop working, but all involved hoped that they would not. Later it did become necessary to reopen the discussion on dying and what it would be like. His parents were able to share their own religious views with him and to assure him that he would not be alone or separated from his parents at any time, which is the chief concern of most youngsters. He never evidenced any fear once he was reassured that all would be done that could be done and that he would not be alone.

Heather also had to face the question of dying and her parents were able to share their deeply held religious beliefs with her and reassure her that she would be at home and would not be alone and would have eternal life. She seemed to evidence no fear of death and looked to it as a release from the pain and sickness that she began to face. She looked forward to seeing her relatives and friends who had died before and to play and play.

For Jeff, dying is a real issue, as the surgeons were not able to remove all the malignant tissue and he continues on maintenance drugs regularly to keep it in remission. The drugs themselves have a very toxic effect on his system and leave him open to infections and viruses. Jeff is concerned about the quality of life open to him now and is eager to live life to the utmost. He and his mother have not talked about death in any depth because both seem uncomfortable with the topic.

On August 5, 1981, Sara made a decision to die and soon. From the day of diagnosis in March 1979, Sara, through discussions with her parents, had been aware that dying was a real possibility for her. She and her parents read the story that appeared in the Des Moines Sunday Register on April 8, 1981, about Elliot, whose drugs had stopped working and who was dying. Sara had discussed the possibility with her parents many times and seemed aware that life for her could be short. She and her family held very deep religious convictions about eternal life and Sara evidenced little fear of dying. On Sara's day of decision in August 1981, the medical team told her and her parents that the current protocol of drugs had stopped working and that in order to continue to stop the progress of the disease, now out of remission, a derivative of interferon would be tried called Poly I, Poly C, which would necessitate a two-week stay in the hospital to receive the drug by injection every day, and the next two weeks of daily injections could be given by Dr. Justin in Mason City. No guarantees were given or promised. It was all very experimental and the end result might be no better than where Sara was right now. Sara began to cry very hard and could not be heard. Then she calmed herself and said to her father and mother,

> "You won't like what I want to do. I want to go off my drugs. I don't want to have them any more. I don't want any more shots. I want to go home."

Sara looked death in the face and made her decision. She knew without the drugs that she would surely die. Not once did she regret that decision or want to take it back. She died to the day two weeks later, unafraid, thanks in no small measure to the counseling and discussions with her parents about death and dying (Warren, 1981).

Social Isolation

Being viewed as different and handicapped by one's classmates brings social isolation for many chronically ill students. Pam spoke of being excluded from a favorite social event of junior high students, roller skating, because she could not do it with her medical restrictions. She felt left out and alienated from her friends and classmates. All the students with cancer who returned to school with bald heads felt social isolation and felt that they were viewed as being unusual. Sara had difficulties having friends come to visit her from her class at school to play at her house. There was no one in her class in her neighborhood and classmates seemed to be reluctant to make the extra effort to be transported out to her house. Her older sister's neighborhood friends shunned her on occasion and would not play with her if Angie was not home.

Elliot, because of his non-attendance at school, became rather isolated at home, except for his best friend and neighbor, Roy, and a close friend from his class who lived in town, Penny, with whom he traded visits. When he was well enough to ride his bike, he visited friends a block or two away for short periods of time. He visited his babysitter's children with his mother but would rarely visit on his own and they came to visit rarely with their parents.

Shelly, her mother related, because of her frequent hospitalizations, feels isolated from her school friends. She has made friends among her fellow patients, several of whom also have cystic fibrosis and are away from their home communities. Her physician has made a special effort to match up patients and to give them opportunities to get to know one another at his clinic, Shelly's mother reported.

Brian reported that he felt different from his friends, getting shots all the time and being concerned about what he ate. His mother stated that he would never let one of his friends see him get an insulin shot because he feared that they would shun him. The friend who was with Brian during the insulin shock episode has remained a friend and "looks out" for Brian at school and on the sports fields. Brian doesn't talk about his diabetes with his friends, his mother reports, and rarely speaks of it even among his family and relatives. Brian competes in sports vigorously and doesn't want his coaches to know about his diabetes because he fears that he wouldn't get to play. He is especially concerned that his wrestling coach will not let him compete in some of the more crucial matches. Brian feels that his mother is over protective of him and is too concerned about his illness. He feels that he is growing up and wants to be more independent and that he can take care of himself. Shelly, reports her mother, certainly feels that way about her efforts to watch out for her daughter's health. Shelly feels that her independence is threatened by her cystic fibrosis and that she can't ever be on her own without having to rely on her doctors, her drugs, and her parents.

Heather and Elliot were probably overprotected by their parents and did not develop socially as did others of their ages. They played and interacted with each other and their fellow patients while both were in Iowa City for lengthy periods for radiation and became good friends. As their illnesses became more serious, they regressed to a very young child state, becoming less independent and self-directed. Heather was very deeply affected by Elliot's death and her parents worked with her to ease her agony.

Sara's mother would have liked to have put her in a bubble and kept her there to protect her from all germs and viruses. With the chemotherapy, the white blood cell count goes dangerously low. The immune system of the body is compromised and infections and viruses can easily invade. Sara could not go to school at these times and a tutor would come to her home. Other students in the family brought home germs, however, so Sara's mother was always concerned.

Career Planning

Career plans are a concern of these chronically ill students. For Pam, her plans to be a model or an actress may have to undergo modification as walking well is an important part of both of these careers and Pam's joints will not let her assume that free and easy grace so admired in these two glamorous vocations. Gary plans to be a math teacher and seems to be well on his way. His health does not appear to stand in his way at this point. Brian would like to be a professional athlete but realizes that his health may not allow it. He is also considering coaching or becoming an athletic trainer. Shelly may have to reconsider her plans to become an airline flight attendant, as her lungs may not be able to stand the altitude even with pressurized cabins and the work may be too physically demanding. Jerry has investigated several careers that involve hard physical labor through the Career Information System of Iowa and is currently leaning towards some type of custodial-maintenance vocation which may be all right unless there is a change in his health picture. Jerry is reluctant to consider any occupations which require training beyond high school or that are intellectually demanding as he feels he is not smart enough for them. Jeff will have to consider his blindness in choosing a career, but he would like a sales position like his new stepfather has, so he says at age six.

Parental Reaction

Each parent or set of parents expressed their reactions to the diagnosis of the illness of their child. This was a shattering experience for them all and each case story reflects the agony and anguish felt on that day. Most described their feelings as being in a daze or total shock and being devastated by the verdict. Most reported feelings of guilt--"if only we'd done this or that"--and felt somehow they had failed in their responsibilities as parents. They had been charged with raising this child and suddenly they could not protect him/her from a dreadful disease. Where had they failed? Some, apprised of a poor prognosis, wept for the adult that their child or adolescent might have become and began the phase of anticipatory grief. All felt anger at the injustice of this happening to their family and to their child. The task of explaining to their child or adolescent the implications of the diagnosis and the treatment regimen was almost as difficult as assimilating the diagnosis itself. The first days of induction and radiation, striving for a remission, were remembered in a blur of hospital treatment rooms, white-coated medical personnel, drugs with unpronounceable names, and treatments that hurt their child or adolescent.

Protectiveness

All parents became very protective of their child or adolescent and resisted the advice to try to treat the child as normally as possible because he/she will probably survive and shouldn't have the additional burden of social maladjustment in later years. These parents had to explain to their other children what the diagnosis meant and why their brother or sister got so much special attention and spent so much time in hospitals and doctors' offices. These parents had to balance their time with the well children at home and home responsibilities with their overwhelming concern that their sick child have the best care, the best chance, and the finest treatment possible. Pam's parents spoke of "shopping for a cure," which they considered strongly. They considered traveling to various world-famous clinics for arthritis to find the place with the best possible drugs and the newest treatment techniques. They chose to go to the Mayo Clinic near home and have felt that their choice was a wise one. Jeff's mother was terrified of the diagnosis and simply wanted to run away. She saw her marriage to Jeff's father begin to break up, saw an attempted reconciliation after the diagnosis fail, and finally went through a divorce.

Siblings' Reactions

Jeff's mother spent as much time as possible with Jeff to the extent that her older son, Jason, age 9, began to resist and resent both Jeff and his mother. Jason was referred for group counseling and attended sessions regularly to "let off steam" and work through his angry feelings and his fears about possible illness in himself.

Sara's older sister, Angie, found it very difficult to understand what was happening to Sara and resented the time and energy her parents spent with Sara to the point of great jealousy and resentment towards her. Only when Angie went along a few times to Dr. Justin's clinic and then to Iowa City with Sara and her parents did she begin to understand what Sara was going through. She began to see why her parents were so worried and distracted at home and seemed to have less time for the other children in the family.

Jerry's and Gary's medical bills and extra travel expenses added financial hardship on already heavily burdened large families. Jerry's older brother has suffered great mental anguish at his brother's illness and the family's financial straits and has serious behavioral problems.

School Relations

Most parents felt that the schools were doing a pretty good job helping their students, but all wished communication between home and school could be improved and that more attention could be focused on their child or adolescent whenever they were going through a particularly tough treatment schedule, were feeling depressed about their condition or prognosis, or had lost a remission. Parents said the loss of a remission was as bad as the original diagnosis and sometimes worse. The parents also mentioned that when their child or adolescent lost a friend through death from their particular disease, the student needed extra support. If academic progress was being affected of behavioral problems began appearing, parents wanted to know immediately. If special programs or services were needed for their student, they wanted to cooperate in every possible way. They hoped that school personnel would be understanding of the necessity for numerous absences for treatment, especially in the early days of the disease when maintenance of a remission is so crucial. Make-up work should be done and on time, but occasionally it was hoped that extra time could be given so as to get an explanation of the material. Gary, particularly, had a problem with a math teacher who did not understand the reason for his absences and expected him to have his work done upon his return with no explanation of the assignment. She would send him to the blackboard and humiliate him if he didn't have it done by making him stand there until he figured out how to do the problems.

Shelly's teachers were not as tolerant of her absences as they might have been, Shelly's mother felt, and seemed to pile on the homework and expect it to be done in an unreasonably short period of time.

Brian's mother felt that Brian's coaches should know exactly what was happening in Brian's case and what to do in case Brain went into insulin shock and that each year they should check for an update on his condition and his disease status.

No parent reported a direct contact with or from a counselor except Brain's mother who reported that his junior high counselor had called her to get suggestions for literature that he could read on diabetes and that he had attended one or two sessions of the Juvenile Diabetes Association chapter meetings in the community. Jeff's mother was pleased about the group counseling that her son, Jason, received under the auspices of the Area Education Agency which had been arranged by his elementary principal.

CHAPTER V

Implications for Counselors

The counselor should view the chronically ill student as a very unique individual who deserves all the support and understanding possible as he/she battles with a life-threatening disease. The counselor should be committed to the belief that this type of student deserves the highest quality of life possible and that the school plays an important part in these students' lives. The counselor would be an ideal person to become the liaison for the student and to facilitate his/her reentry to school after the initial diagnosis and treatment. The counselor would be more effective as he/she became knowledgeable about the type of illness that the student has so as to become a resource person for teachers and students. He/she should become aware of any limitations that the student is medically required to observe and disseminate that information to school personnel who will have contact with the ill student, notably physical education teachers, coaches, and classroom teachers who might be called upon to deal with a classroom emergency. The counselor should work closely with the school nurse. A meeting of school personnel should be set up to apprise those who will work closely with the student, and the student, his/her parents, and if possible, representatives of the medical team should be in attendance. The student will then be able to hear what is said to his/her teachers, will be able to answer questions as to how he/she feels, his/her concerns about peers' reactions, apprehensions about make-up work, ability to keep up, physical changes in him/her that are evident.

The counselor with the administrators should help to establish guidelines as to when make-up will be due and will help to lay out a plan with the faculty to individuate the school program as it affects this particular student. The student's treatment schedule should be well known by teachers who will then be aware of the reasons for the student's absences. Any physical barriers to the student's reentry should be discussed at this time and if a physical therapist is on the medical team, assist the student in overcoming these. If not, the counselor and the administrators can work with the student.

If transportation needs to be arranged through the school or through an Area Education Agency, the special services divisions of the transportation department of both organizations will need to be contacted.

An early problem may be the necessity for a tutor to arrange for the students to catch up. The hospital social worker assigned to each student may have already contacted the school for help and guidelines in this regard and the counselor may have already taken care of this concern. The question as to whether the tutor will be the primary educator for a period of time with the student auditing regular school classes should be made at this meeting. If a regimen of radiation is upcoming at a tertiary care facility some distance from the student's home town, this might be a wise consideration. In such facilities there is a tutoring team that works closely with the students' own schools and has almost all the textbooks currently in use in the state's schools. The hospital tutoring team calls regularly to the school for assignments and checks with teachers on deadlines.

The assemblage of school personnel, the student, his/her family, and representatives of the medical team should gather together each semester to revise and reevaluate the individuation strategies in the light of the student's progress and hopefully improving health.

If the student is in treatment, it may be necessary for him/her to take medication during school hours, have snacks, take rest periods, and go to the restroom occasionally from class. Teachers need to be comfortable with the idea of remission. If a student is in school, he/she feels well enough to be there and should be treated normally.

The counselor should begin a regular series of interactions with these students, generally on a weekly basis, during study halls or study time in classes for at least thirty minutes to check academic and social interaction. Teachers should be made aware of this ongoing relationship so that concerns and problems can be referred to the counselor.

The student should be present when his/her classmates are told about his/her disease and should be encouraged by the counselor to answer his/her classmates' questions. The counselor should also be present at this class session when the student reenters school. He/she and the school nurse may also want to offer their services as supplemental speakers to health or science classes throughout the school on questions of chronic illnesses. In order to become knowlegeable about the various chronic illnesses, the counselor would do well to attend American Cancer Society presentations, Juvenile Diabetes Association meetings, the Juvenile Rheumatoid Arthritis Foundation sessions, and those of other like organizations as well as read each organization's literature. In the case of students with cancer, the counselor would want to get in touch with the nearest chapter of the Candlelighters or any like support group for parents that is meeting for his/her own information and the information of the parents of his students who already may be members.

After the student reenters school the counselor should continue to get regular reports and updates on the student's medical condition from the medical caregivers, and if he/she has questions about the student, contact should be made.

Arrangements should be made for the student to come to the counselor's office whenever he/she felt that he/she wanted to talk with the counselor but in the course of the regular weekly meeting the counselor can begin working with the student on coping mechanisms, notably with stress, using the centering activities of Gay Hendricks in both elementary and secondary settings. The meditation techniques such as Counting Breaths, Combating Negative Things to You, and Relaxing the Mind are excellent (Hendricks, Wills, 1975). For high school students, Burns' (1980) "Double Column" techniques from Feeling Good is a way to build self-esteem and combat stress. The Automatic Thought of Criticism on the left-hand side can be answered with rational responses on the right-hand side so that the counselor can help the student formulate. Greenberg's (1980) large muscle activities from Coping With Stress on the Job can also be explored. They will work even for handicapped students as the LMA techniques are mainly walking and stretching. Greenberg's "Do Nut Concept" about anger will also help the ill student analyze his/her feelings, as will role playing difficult situations with unsympathetic teachers and peers. The student needs a period of time to work through these feelings, as his/her body has been invaded first by a life-threatening disease and then by many medical caregivers to treat that disease (Kushner, 1981). The basic angry question has to be, "Why me?" Any question that the counselee is at fault for his/her disease or that this is punishment for past misdeeds or that the counselee in any way deserves what has happened to him/her must be worked through in order to build self-esteem up once more. The ill student must work through the reactions of his/her friends and peers to what has happened and the implications of this disease. Many peers are cruel and involve the student in social interaction only to tease him/her. Kushner (1981) also speaks of Schadenfreude, which friends of chronically ill students suffer. It refers to an embarrassing reaction of relief that friends feel when something bad happens to someone else instead of to them. Friends of chronically ill students may try to relieve this feeling by saying to themselves that there must be a reason why it happened to someone else, and they tend to blame the victim. The ill student needs to work through the pain of the teasing and seeing his friends withdraw and to learn to reach out to them, ask for their help, and make them feel comfortable. The ill student must be reassured that life is unfair and that he can cope. Johnson (1981) gives five factors that have helped people survive in concentration camps, cancer and heart disease, and old-age difficulties:

> 1. Having deeply held goals and committments and turn concern outward to help other people.
>
> 2. Sharing your distress with other people. Passive and accepting well-behaved people die. Those who aggressively get their needs met tend to live.
>
> 3. High morale is important. Depression kills.
>
> 4. Physical activity is an important survival factor.
>
> 5. Friendships and love relationships are vital. Lovely people die. People with good friends and loving relationships survive. . .

Building self-esteem and coping with painful situations is further enhanced by learning about the types of distorted thinking that can interfere with interactions with others. If an ill adolescent can realize the way in which he/she may be thinking about a situation, it will have an effect on how he/she feels about that situation.

Types of distorted thinking that may be affecting a chronically ill student's stress level are:

1. All or nothing--anything short of perfection is total failure.
2. Overgeneralization--seeing a single negative event as the way it will always be.
3. Mental filter--picking out a single negative detail and dwelling on it so that all of life becomes dark and gloomy.
4. Disqualifying the positives--rejecting positive experiences by saying they "don't count" for some reason.
5. Jumping to conclusions--giving a negative interpretation with no definite facts to support the conclusions, either by assuming someone is reacting negatively to you or anticipating that things will turn out badly.
6. Magnification or catastrophizing--maximizing the importance of your goof and minimizing your own desirable qualities.
7. Emotional reasoning--assuming that negative emotions reflect the way things really are--"I feel bad, therefore, I must be bad."
8. Should statements--motivating oneself with shoulds and musts, punishment is necessary before you can be expected to do anything.
9. Labeling and mislabeling--attaching a negative connotation to yourself--"I'm a loser."
10. Personalization--feeling that one is responsible for a negative event (Burns, 1980).

The feelings of hostility about treatment and hospitalization need to be worked through as these experiences give rise to a sense of helplessness and anger. Talking them out with a counselor outside of the family helps and does not make the ill student's family feel guilty and anxious about putting their son or daughter through all that.

Fears of the chronically ill student must also be discussed, the fear of a relapse and having to go through reinduction, which means using different drugs but repeating the original treatment schedule trying for another remission, usually accompanied by radiation therapy. This is a painful, anxiety-causing series of sessions because the new drugs usually have different side effects though generally all cause nausea and vomiting. The fact of a relapse means that the drugs have stopped working and reminds the student that all the drugs could stop one day and the disease will take the student's life. The fear of death and dying may not be something a student will feel comfortable discussing early in the sessions, but if the counselor is empathic and seems comfortable and willing to talk about death and is truly concerned about the student, the student will speak of this topic which is probably uppermost in his/her mind, certainly within six months after diagnosis or if he/she has been hospitalized recently or has had a relapse. Talking through these fears and expressing his/her anxieties about the life-threatening aspects of his/her disease will help the student cope much more adequately with his/her illness. If his/her family has difficulty in talking with him/her about the possibility of death, it is usually because for most parents it is too difficult to speak of with their child/adolescent. If this is the case the student has been very lonely and scared, keeping all these fears to himself/herself. Many students may prefer to talk this over with their pastor, priest, or minister, but a number have no one they feel close enough to that will not be overwhelmed by the discussion, particularly most of their peers. Younger students need to talk of the possibility of death at their level of understanding and to realize that support, both physical and emotional, will be there from those they have trusted. An emphasis in these discussions must be placed on the quality of life. People can die at any time and therefore everyone needs to live each day in a caring, committed way to maximize their potential and live life to the fullest.

A school counselor in a large high school or a junior high school may have several chronically ill counselees within the school. A support group of these students may be formed so that they may talk with each other, work through mutual problems, and ease the social isolation that all may feel. The physicians who serve as primary caregivers for tertiary care centers, such as the University of Iowa or the Mayo Clinic in Rochester, may treat a number of chronically ill patients for their maintenance therapy. Names of a number of chronically ill students could be gotten this way and a group formed. Students who live in rural towns may be served by being added to this group, which could meet in the organizing counselor's school or the school's central offices. Dr. Margaret Blake (1981) in a Group Processes workshop suggested that groups of students with like problems can be very effective and satisfying to participant and facilitators alike. Her experience had been in a large city school system with elementary girls that had been victims of incest. They met for a once-a-week group counseling session in the central administration offices. Such a support group for students is in the planning stages in Mason City as an outgrowth of the parents' support group led by Reverend Brasel and Jana Grady at Mercy Hospital. They have had social events involving the families of the support group, which helped the chronically ill children/adolescents to get together and get acquainted.

Counselors who have an established, ongoing Peer Helping class in their junior highs or high schools have a way to help chronically ill students with the problem of social acceptance and participation in social activities. The Peer Helpers can become the student's friends when he/she has no other, can assist with make-up work and can tutor the student from time to time, can help with the student's mobility around school, can with the counselor keep in touch when the student is absent from school for treatment, can visit the student in his/her home from time to time and at the hospital if the treatment center is close, and can ease the student's reentry into school after a lengthy absence when they may be physically changed and mentally depressed.

Counselors should encourage chronically ill students to be as independent as possible whether six or sixteen, do for themselves whatever they are physically and mentally able to do, and provide support to help them to do it. Counselors should help these students plan for careers and occupations, compensating for any disabilities they might have. By using the Career Information System of Iowa, a counselor can help students explore careers that they are physically and mentally capable of doing. Students should be encouraged to choose challenging careers that will demand their full potential.

Counselors need to be aware of organizations that are supportive for the chronically ill student (see Appendix III) and refer students and families to organizations that are applicable. Counselors can get information and literature for their own knowledge from these groups, also. Counselors need to also be knowledgeable as to the financial aid available for these students, both while attending high school and for post-high school educational plans. The counselor should work closely with the families and the government agencies as well as the vocational rehabilitation counselor assigned to them. The hospital social worker assigned to each student can be helpful here, also. The Social Security Administration is one source of aid, even for elementary students.

Special services needs for students, such as tutors or special teachers, can be arranged for by the counselor in cooperation with the administrators.

School counselors should be aware that there are summer camps for chronically ill students. There are three fairly new cancer summer camps in the United States with a medical center at each to dispense drugs and check blood counts. All the normal activities that kids do at camp are sponsored here, and all types of cancer patients are welcomed. One of the favorite dart games at the camp is a dummy in the form of a doctor and the darts are hypodermic needles which the kids are most happy to throw. Several of the *counselors have had cancer and the campers feel really comfortable* talking about their feelings with these young adults. They can discuss fears of death and dying at any time and any other concerns. The Cancer Information Service has the information on locations and applications (Kuralt, 1981).

Counselors can provide services to the families of chronically ill students as well, particularly the siblings of these students. The siblings need sessions that just check to see where they are. The ideal situation for these students would be a support group for the siblings as a group counseling set-up. Their hostility at living in a family where one member is so different needs to be understood and worked through as well as their fears of the possibility of the death of their brother or sister, resentments at all the special attention the ill child/adolescent in the family is getting, and their own sense of social isolation and their family's social isolation.

If a parent support group is not in place or readily available to parents of chronically ill students, one could be started by an interested counselor, perhaps in conjunction with the Candlelighters Foundation, a national organization for the parents of cancer patients. In a rural area there may be only one set of parents so afflicted, but counselors could offer their services or refer them to a group in surrounding communities. Some families might benefit from meeting with the school counselor as a family group, with the ill child/adolescent also in attendance. The counselor can help with communication and the expression of feelings (Spinetta, 1981). Fathers, particularly, don't get much professional support from the medical team because they are usually at work and rarely talk to health professionals (Des Moines Sunday Register, 1981). A school counselor might be more accessible. Parents would also have a chance either with a counselor alone or in a support group to discuss parenting a chronically ill child and setting limits for him/her. When a child is ill, idealization of the child can occur and parents overlook normally unacceptable behaviors because the child/adolescent must suffer with the disease and the treatments (Belle-Isle, 1979).

Counselors can give aid to the teachers of chronically ill students by offering their skills in a consultant's role. Most counselors have spent a number of years in the classroom and can share teaching strategies and evaluation techniques that will help answer the question of how to teach such a student and how to evaluate a repeatedly absent student. Testing can be done by the counselor to determine the intellectual capacities of the student and the counselor can check with the parents, the school nurse, and the medical team regularly to answer questions about his/her medical condition and ascertain whether the teacher should push for participation and completion of classroom work at this particular time or ease off a bit to let the student regroup his/her resources. The counselor can work closely with the school nurse as to procedures for medical emergencies, and in the absence of a school nurse, the counselor might consider becoming certified as an Emergency Medical Technician or at the very least complete a CPR course so as to handle any life-threatening situations.

The counselor can work with the administration to write realistic promotion policies for often absent students and work with classroom teachers to help the student achieve success by regular conferences with both student and teacher. Hopefully, a situation that involved Felicia Flynn in Natick, Massachussetts, could be avoided with careful counselor concern. Felicia, a senior and a Hodgkin's disease sufferer, was two credits short of enough credits to graduate. She had been absent many days for hospital visits and treatment. The school had refused to let her retake a failed biology test. She was not allowed to participate in the school's graduation ceremonies and receive a blank diploma (The Messenger, 1982).

The counselor can serve as a consultant and resource person for classroom units on Death and Dying. They may supply information, may serve as a supplemental speaker, may help contact community resource persons and experts. The counselor may become involved in a hospice movement. The hospice movement consists of a group of volunteers who assist a family with a dying member in order to help keep him/her home as long as possible and to ease the grief of the family. Persons from this group are more than willing to share their experiences. The counselor may set up a structured group experience for students who are bereaved and help them work through their grief. The counselor can also set up a group of teachers who work with chronically ill students to allow them to express their feelings about the possibility of the death of these students.

Counselors would do well to explore and become knowledgeable about the relationships now being researched between the mind and body and the effects on one's health. They would do well to pursue the study of intervention strategies for better coping with stress to prevent physical illness in counselees rather than depending on the medical teams to intervene after the fact.

Summary

Students who were previously dying of diseases such as leukemia and Hodgkin's disease are now being saved and are returning to school in ever greater numbers and for longer periods of time, many of them permanently. They are called chronically ill students because they must undergo lengthy treatment, generally over a time span of three years. Other diseases in this category, such as cystic fibrosis, share with the cancers a long period of maintenance therapy. These students have great psycho-social needs. Peers and school personnel have great difficulty in relating to all that the student has gone through in order to continue to live. Many of these students, while undergoing treatment, are socially isolated at a time of their greatest need for support.

The quality of life for these students is all-important, not the quantity of years. The school experience is a very valuable part of their life experience. Yet for many it is distressing and disturbing. Counselor support can make a crucial difference, assisting these students in coping.

Elementary counselors are needed to help, particularly the victims of leukemia, the most common childhood cancer. Secondary counselors need to set up support groups for both students and parents. A Peer Helping class is invaluable for assisting chronically ill students. Death and Dying education needs to be a part of the school curriculum, and the counselor can serve as a consultant to school staff members during its implementation.

The counselor can serve as a consultant to administrators and teachers in solving and evaluating the academic, social, and psychological concerns within the school setting regarding chronically ill students and their individual needs.

The counselor can provide for chronically ill students' supportive and therapeutic options that can help these students effectively cope with their disease and positive treatment and make a difference in their school experience.

BIBLIOGRAPHY

Baker, Lynn S. You and Leukemia, A Day at a Time. Rochester, Minn.: W. B. Saunders, 1977.

Belle-Isle, Joann, Barbara Conradt. "Report of Discussion Group for Parents of Children with Leukemia." Maternal and Child Nursing Journal. 8(1):49-58, Spring 1979.

Binger, C. M., A. R. Ablin, R. C. Feruerstein, J. H. Kushner, S. Zoger, C. Mikkelsen. "Childhood Leukemia Emotional Impact on Patient and Family." New England Journal of Medicine. 1969, 280. pp. 414-418.

Blake, Dr. Margaret. "Group Counseling Skills." Counselor Skill Development Workshop. University of Northern Iowa, Cedar Falls, Iowa. March 30-31, 1981.

Bogdan, Robert, Steven J. Taylor. Introduction to Qualitative Research Methods. New York, Wiley, 1975.

Brasel, Rev. James. Chaplain, St. Joseph's Mercy Hospital, 84 Beaumont Drive, Mason City, Iowa 50401. Counselor, Pediatric Oncology Support Group. May 9, 1981, at St. Joseph's Mercy Hospital.

"Price of Survival in Childhood Leukemia." British Medical Journal. 1(6109):321-22, February 11, 1978.

Brody, Jane E. "'War on Cancer' Sees Significant Victories." The New York Times News Service. Cedar Falls Record. Cedar Falls, Iowa, April 23, 1981. p. 11, cols. 1-2.

Burns, David D., M.D. Feeling Good, The New Mood Therapy. New York: New American Library, 1980. pp. 9-416.

Burns. W. J., and A. R. Zweig. "Self-Concepts of Chronically Ill Children." Journal of Genetic Psychology. 137:179-190, December, 1980.

Cancer Information Service, National Cancer Institute. Bethesda, Maryland. Telephone 1-800-638-6694.

Career Information System of Iowa. Computer Disk for Apple II, Process Users Handbook, Occupational Briefs, Program Statements. Department of Public Instruction, Grimes Office Building, Des Moines, Iowa.

Carkhuff, Robert R., PH.D., et al. The Art of Helping IV. Amherst, Mass.: Human Resources Development Press, Inc., 1981. p. 248.

CBS Sunday Morning News. Cancer Kids. 15-minute segment narrated by Charles Kuralt, Host, September 20, 1981.

Chapman, K. "Chronically Ill Child in the Normal Classroom." Orbit. 11:3-5, December, 1980.

Dannenbring, F. G., M.D. Pediatrician, Fort Dodge Medical Center, 300 South Kenyon Road, Fort Dodge, Iowa 50501. May 18, 1981, at Fort Dodge Medical Center.

Davison, Jean, R.N. Oncology Practitioner, University of Iowa Hospitals and Clinics, Department of Pediatric Hematology-Oncology, University of Iowa, Iowa City, Iowa 52242. May 4, 1981, at University of Iowa.

Eiser, Christine. "Intellectual Abilities Among Survivors of Childhood Leukemia as a Function of CNS Irradiation." The Archives of Diseases of Childhood. 53(5):391-395, May, 1978.

Evans, Joyce, Nancy Needle. "Helping Relationships, Supporting Chronically and Terminally Ill Children in Hospitals: A Challenge for Educators." Education Unlimited. November-December, 1980. pp. 22-27.

Frydman, Michael. "Perception of Illness, Severity and Psychiatric Symptoms in Parents of Chronically Ill Children." Journal of Psychomatic Research. 24(6):361-369, 1980.

Greenberg, Herbert M. Coping With Job Stress. Englewood Cliffs, N.J.: Prentice-Hall, Inc., 1980. pp. 7-270.

Greene, P. "The Child With Leukemia in the Classroom." American Journal of Nursing. 75:86-87, 1975.

Hartman, Joan B. Taking Time, Support for People With Cancer and the People Who Care About Them. U. S. Department of Health and Human *Services, National Cancer Institute, Bethesda, Maryland, September, 1980. pp. 1-63.*

Haynes, Alphonso W. "The Challenge of Counseling the Homosexual Client." Personnel and Guidance Journal. December, 1977. pp. 243-246.

Hendricks, Gay, Russel Wills. The Centering Book, Awareness Activities for Children, Parents and Teachers. Englewood Cliffs, N.J.: Prentice-Hall, Inc., 1975. pp. 1-178.

----------, Thomas B. Roberts. The Second Centering Book, More Awareness Activities for Children, Parents and Teachers. Englewood Cliffs, N.J.: Prentice-Hall, Inc., 1977. pp. 1-322.

Interviewed Students and Parents

Brian, age 14, and mother. May 20, 1981, Cedar Falls, Iowa.

Gary, age 14, and mother. May 15, 1981, Fort Dodge, Iowa.

Heather, age 8, and parents. May 24, 1981, rural Iowa.

Jeff, age 6, and mother. June 4, 1981, rural Iowa.

Jerry, age 16. April, 1982, rural Iowa.

Pam, age 13, and parents. May 17, 1981, Fort Dodge, Iowa.

Sara, age 7, and parents. Radio interview by Cynthia Feustal, KCMR-FM, Trinity Lutheran Radio Network, Mason City, Iowa 50401. Broadcast March, 1980.

Sara, age 7, and parents. May 9, 1981, Mason City, Iowa.

Mother of Shelly, age 14. June 19, 1981, Fort Dodge, Iowa

Wendy, age 7, and parents. May 16, 1981, rural Iowa.

Isaacson, Ruth. Pediatric social worker, University of Iowa Hospitals and Clinics, University of Iowa, Iowa City, Iowa 52242. May 4, 1981, at University of Iowa.

Johnson, David W. Reaching Out, Interpersonal Effectiveness and Self-Actualization. Englewood Cliffs, N.J.: Prentice-Hall, Inc., 1981. "Acceptance of Self and Others." pp. 171-193. "Confrontation and Negotiation." pp. 229-249. "Anger, Stress and Managing Your Feelings." pp. 251-283.

Justin, John, M.D. Medical Arts Building, 1312 4th Street SW, Mason City, Iowa 50401. May 8, 1981, at Medical Arts Building.

Kellerman, Jonathan, David Rigler, and Stuart Siegel. "Psychological Response of Children to Isolation in a Protected Environment." Journal of Behavioral Medicine. 2(3):263-274, 1979.

Kisker, C. Thomas, M.D. Professor of pediatrics, and Dr. Raymond Tannous. Associate professor of pediatrics, University of Iowa Hospitals and Clinics, Department of Pediatric Hematology-Oncology, University of Iowa, Iowa City, Iowa 52242. May 4, 1981, at University of Iowa.

Koocher, G. P., et al. "Psychological Adjustments Among Pediatric Cancer Survivors." Journal of Child Psychology and Psychiatry. 21:163-173, April, 1980.

Kushner, Harold S. When Bad Things Happen to Good People. New York: Schocken Books, 1981. pp. 1-149.

Lindner, Mary Lou, R.N. Pediatric hematology-oncology nurse, University of Iowa Hospitals and Clinics, Department of Pediatric Hematology-Oncology Clinic, University of Iowa, Iowa City, Iowa 52242. May 4, 1981, at University of Iowa.

May, Rollo. The Art of Counseling. Nashville, Tenn.: Abingdon, 1980. pp. 15-247.

McCarthy, M. "Social Aspects in Treatment of Childhood Leukemia." Social Science and Medicine. 9:263-269, September, 1980.

"Graduate." United Press International dispatch. The Messenger. Fort Dodge, Iowa, June 15, 1981. p. 3, col. 1.

"Computer Terminal Centerpiece of Don Linville's Existence." The Messenger. Fort Dodge, Iowa, June 15, 1982. p. 17.

Moore, D. C., C. P. Holton, and G. W. Martin. "Psychologic Problems in the Management of Adolescents with Malignancy." Clinical Pediatrics. 8(8):464-473, August, 1969.

National Cancer Institute, a. Coping With Cancer. An Annotated Bibliography of Public, Patient and Professional Information and Education Materials. Cancer Information Clearing House, Office of Cancer Communications, National Cancer Institute, Bethesda, Maryland, May 1980. pp. 42-54, 69-74, 84-93.

National Cancer Institute, b. Students with Cancer, A Resource for the Educator. Bethesda, Maryland: National Cancer Institute, with the Washington, D.C., Metropolitan Candlelighters and Department of Pediatric Hematology-Oncology, University of Kansas Medical Center, Kansas City, Kans., January 1980. pp. 1-24.

Nelson, Richard C. "Counselors, Teachers and Death Education." Death Education, Pedagogy, Counseling, Care--An International Quarterly. 24(5):322-329, May, 1977.

O'Malley, J. E. "Psychiatric Sequelae of Surviving Childhood Cancer." American Journal of Orthopsychiatry. 49:608-616, October, 1979.

Pendleton, Edith (comp.). Too Old to Cry . . . Too Young to Die, 35 Teenagers Talk About Cancer. Nashville, Tenn.: Thomas Nelson Publishers, 1980.

Pick, Barbara. "Effects of Childhood Cancer on Long Term Survivors and Their Families." British Medical Journal. 1(6174):1327-1329, 19, May, 1979.

Pusateri-Vlach, N. F., J. C. Moracco. "Counseling Intervention in Cancer Therapy." Personnel and Guidance Journal. 59:267-273, January, 1981.

"Fathers Surveyed on Children's Illnesses." Knight Newspapers Syndicate. Des Moines Sunday Register, Des Moines, Iowa, Home and Family Section, October 18, 1981. p. 4, cols. 1-2.

Sachs, M. B. "Helping the Child With Cancer Go Back to School." Journal of School Health. 50:328-331, August, 1980.

Schweers, Eugenia, Patricia Farnes, and Edwin Forman. Parents Handbook on Leukemia. Providence, R.I.: American Cancer Society, Rhode Island Hospital, 1977. pp. 3-60.

Seidl, A. H., A. Atlshuler. "Interventions for Adolescents Who Are Chronically Ill." Child Today. 8:16-19, November-December, 1979.

Shapiro, Deane H. Jr. Precision Nirvana. Englewood Cliffs, N.J.: Prentice-Hall, Inc., 1978. pp. 2-344.

Sherman, Mikie. The Leukemic Child. Bethesda, Maryland: Office of Cancer Communications, National Cancer Program, National Cancer Institute, March, 1979. pp. 3-80.

Spinetta, John J., Joyce A. Swarner, and John P. Sheposh. "Effective Parental Coping Following the Death of a Child from Cancer." Journal of Pediatric Psychology. 6(3):251-263, 1981.

Stehbens, James A., Mary E. Ford, C. Thomas Kisker, William R. Clark, Faye Strayer. "Wisc-R Verbal Performance Discrepancies in Pediatric Cancer Patients." Journal of Pediatric Psychology. 6(1):61-68, 1981.

Strayer, Dr. Faye. Research scientist, Department of Pediatrics, University of Iowa Hospitals and Clinics, Iowa City, Iowa 52242. Telephone interview, June 25, 1982.

Swift, P. "Price of Survival in Childhood Leukemia." [letter]. British Medical Journal. 1(6118):986-7, April 15, 1978.

Tiller, J. W. "Family Reactions in Childhood ALL in Remission." Australian Paediatric Journal. 13(3):176-181, September, 1977.

Warren, Nancy, a. "Essay on Day of Decision by Sara Tompkins." Description of clinic visit by Sara, Angie, Richard and Jayne Tompkins and author on August 5, 1981, University of Iowa Hospitals and Clinics, Pediatrics Clinic, Iowa City, Iowa. Dr. C. Thomas Kisker, attending physician.

----------, b. "One Day at a Time--Elliot W. Warren's Story." Research paper completed for Seminar on Death and Dying. 68:194g, University of Northern Iowa, Cedar Falls, Iowa. Rev. Don Feuerhak, Adjunct Professor, May, 1981. pp. 1-45.

Yohn, D. S., L. K. Graff. "Progress in Leukemia Treatment." U.S.A. Today. 109:58-60, March, 1981.

Your Guide to Common Cancer Terms. Adria Laboratories, Inc., U.S.A., September, 1979.

APPENDIX I

Questions Asked Chronically Ill Students

1. How are you feeling about school? How was it to go back to school after diagnosis?
2. If you could tell your teachers anything you wanted to, what would you tell them?
3. Are there things about your illness you would find very hard to talk to your teacher about?
4. Do you feel you can talk to your counselor about anything at all, especially your illness?
5. Does your counselor know that your illness is life threatening or seriously debilitating?
6. Can you talk with your counselor about death and dying?
7. How would you feel about a support group to help each other to talk about your illness?
8. What would you say to anyone newly diagnosed with your type of cancer?
9. Are you comfortable talking about your disease to your classmates?
10. How were your classmates told of your illness? Were you there to hear what the teachers were told about your illness? Were you there when classmates were told?

11. When you have to be gone from school for checkups or treatment, do all your teachers know why you are gone? Do your classmates know?
12. If you had a chance to talk to a group of counselors about your disease and your feelings about the kind of help that would be most beneficial, what would you say?
13. What are your future plans when you finish school?
14. Have you talked with your counselor about your future plans? Was your counselor helpful in planning your future?
15. How has your disease affected your plans for the future? A lot of change?
16. How would you feel about your school counselor talking to your whole family from time to time? To discuss family problems and to talk about stresses of your illness?
17. How concerned does your counselor seem to be about what is happening to you with your illness?
18. If you could tell all your classmates about your illness, what would you want them to know?
19. Are you feeling that I am understanding what concerns you have and that I can relate to those concerns? That I'm tuned in to where you are?
20. *What's really not fun about school for you? What's really fun and enjoyable?*
21. Are there days you don't want to go to school? When you don't want to go to school, how does it feel for you?

22. Are you ever feeling that your parents are overconcerned about you, that they try to protect you too much and worry about you too much?
23. Do you ever wonder, why me? Why do I have to have this illness?
24. How are you feeling about you?

APPENDIX II

Questions Asked Parents of Chronically Ill Students

1. How did you feel on the day of diagnosis? How did you tell your child?
2. How did you handle the implications of treatment and prognosis?
3. How did you handle the feelings of wanting to protect your child from all harm and helplessness at being unable to protect them from this disease?
4. How did you handle the reactions of siblings to all the attention and special treatment given to the patient?
5. How well did you feel that the schools handled the special needs of your child?
6. Was there a counselor involved in helping your child at school? Would you have liked to have one if absent?
7. Do you feel you would benefit from a parents' support group led by a counselor?
8. Do you have any suggestions for improvement of your child's school experience?

APPENDIX III

Supportive Organizations

Office of Cancer Communications
National Cancer Institute
Bethesda, MD 20014

American Cancer Society
219 East 42nd Street
New York, NY 10017

Leukemia Society of America, Inc.
211 East 43rd Street
New York, NY 10017

Candlelighters
123 C Street S.E.
Washington, D.C. 20003

Make Today Count
218 South 6th Street
Burlington, IA 52601

Compassionate Friends
424 West 6th Street
Cedar Falls, IA 50613
(319) 266-9314

Cancer Information Service
National Cancer Institute
Bethesda, MD 20205
800-638-6694

Ronald McDonald House
Iowa Methodist Medical Center
1200 Pleasant Street
Des Moines, IA 50308
(515) 283-6212

Cancer Information Clearinghouse
7910 Woodmont Avenue, Suite 1320
Bethesda, MD 20014

Juvenile Diabetes Association
Iowa Affiliate
5270 North Park Place N.E.
Waterloo, IA 50703

Juvenile Arthritis Foundation
Iowa Chapter State Headquarters
914 Locust Avenue
Des Moines, IA 50311

Amanda the Panda
(Jo Ann Zimmerman)
4116 65th Street
Des Moines, IA 50322
Home Phone: (515) 276-2634

or

Catholic Council for Social Concern
700 3rd Street
Des Moines, IA 50309
(515) 243-4259

Visits terminally ill children in panda costume--a caring presence.

APPENDIX IV

Interviewed Students Counselor Contact

Name	Counselor Available in School Building	AEA Contact	Talked With Counselor
Elliot	No	No	
Heather	No	No	
Wendy	No	No	
Sara	No	No	
Jeff	No	No*	
Shelly	Yes	No	Some
Brian	Yes	No	Rarely**
Jerry	Yes	No	Some
Gary	Yes	No	Often
Pam	Yes	No	Rarely**

*Brother, age 9, counseled by AEA counselor

**Encouraged by parents to do so

Responses:

Never
Rarely
Some
Often
Regularly