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ABSTRACT

Originally presented as a paper at a 1974 Conference on Psychiatric Problems of Childhood, the pamphlet presents a discussion of the psychosocial aspects of adjustment and management of leukemia in children and youth. The increasing length of remissions in acute lymphocytic leukemia is thought to require physicians to consider nonmedical needs of their patients. Discussed are the medical management of the illness, the sharing of diagnoses and protocols with the children and families, the initial period of adjustment before remission is obtained, the periods of adjustment during the course of remissions and relapses, and life planning (including communication with school personnel, development of friendships, marriage, and employment). (DB)

NIMH report to physicians 2

Psychosocial Management of Leukemias in Children and Youth

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Improved understanding of the etiologic factors in disease and concomitant technological advances enables the medical community to modify many disease processes dramatically. Some conditions previously fatal now take the form of chronic diseases. One example of this in children is leukemia. As currently treated, leukemia no longer has immediately fatal results. Rather, children survive for lengths of time up to 5 and 10 years. While a few survive longer, we hesitate to label them as cured. The child diagnosed as leukemic, then, has a deferred death sentence if he and his family agree to accept modern treatment. This treatment, as well as the disease, produces changes in the child's physique, energy level, and adaptability. This paper* examines various aspects of such chronic yet fatal diseases: (1) the sharing of diagnoses and protocols with the children and families; (2) the initial period of adjustment before remission is obtained; (3) the periods of adjustment during the course of remissions and relapses; (4) life planning (school, independence, intimacy, employment).

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Some Psychosocial Questions

Beginning in the 1960s, in part due to the technologies derived from physics and chemistry, the medical profession has gained the ability to prolong significantly the lives of people who earlier would have quickly died. In these situations cure is not offered. Hope for cure dangles beyond our current reach. Meanwhile, our new possibilities create physical and psychological pains which never before existed.

These new successes now create a major challenge to the medical community. What are the ethics and morality of these dramatic modifications of disease processes? To answer this we must consider and study carefully the quality of life our technologies produce. We must learn from the patients whose lives we prolong; we must learn from their families and their communities. We know relatively little of their experiences with our treatments and with their illnesses. What are their needs? What are their styles of coping? How can we provide care that does more than prolong physical existence, trading death for a purgatory in life? This paper, based both on work at the National Cancer Institute and on the experiences of other clinicians in similar settings, shares the results of early inquiries into the above questions.

The Leukemias

The leukemias of childhood, especially acute lymphocytic leukemia (ALL), no longer have rapidly fatal results. In the 1950s no more than 30 percent of children with ALL lived 1 year from their diagnosis. By 1972 ninety percent survived the first year. Twenty-five to thirty-five percent now survive at 5 years post diagnosis. Some young people are surviving 5 to 10 years, yet the medical community hesitates to label them

as cured. A deferred death sentence with an existence tied to a medical center, pain-producing tests and treatments, physical changes, and changes in energy levels result. Therefore, the leukemias of childhood are presented here as one model for the study of chronic yet fatal illness.

The Illness

The onset of childhood leukemia's symptoms is sudden. Persistent malaise, fever, sore throat, usually lead to a physical examination and a blood count which reveal the probable disease. Sometimes first symptoms are bleeding, joint pain, sudden lymph node enlargement. The change from a completely healthy child to a child diagnosed as leukemic can occur in several days to several weeks. Modern treatment initially demands complete disruption of the patient's and the family's life. Partial disruption never ceases while the child lives. The treatment program may be divided into the broad categories of remission induction, remission consolidation and remission maintenance. Procedures include multiple finger-sticks, lumbar punctures, infusion of antimetabolites into the cerebro-spinal fluid and blood, X-rays, intravenous infusions, and bone marrow punctures. Medications can produce burning sensations during the infusions. Blood veins eventually sclerose. Side effects from treatment include: nausea, vomiting, gastric burning, loss of appetite, bronchospasm, itching, hematuria, cardiac toxicity, peripheral neuropathies (ptosis, foot drop, weak hand grasp), mouth ulcers, rectal fissures, fluid retention, rashes, alopecia, and rarely blindness. Today the newly diagnosed child is hospitalized during remission induction. This hospitalization can last 1 to 3 or more weeks. After that, with the remission consolidation period, the child is treated in the outpatient department. The total

process of remission induction and remission consolidation usually takes 3 to 8 weeks. Thereafter the child comes to the clinic every 3 to 6 weeks during the period of remission maintenance. During this period the patient receives treatment over a 5-day period, spending most of these days in the clinic. Bone marrow and blood samples are taken. This schedule usually lasts 6 months. After this 6-month period, if the child is in remission, all treatment is discontinued until the child relapses. When there is a relapse the treatment procedure begins anew in an attempt to get a remission reinduction. At this time it is not unusual to introduce new medications which have different side effects than those already experienced by the child.

The above sketch of acute lymphocytic leukemia and its treatment is a necessary background to an examination of four psychosocial aspects of the disease:

1. The sharing of diagnoses and protocols with the children and families
2. The initial period of adjustment before remission is obtained
3. The periods of adjustment during the course of remissions and relapses
4. Life planning

Sharing Diagnoses and Protocols

In many quarters the debate continues over whether or not to reveal the diagnosis and explain the treatments to the child. Sometimes this debate between members of the medical profession takes the apparent form of active behind-the-scenes disagreement between the treating physician and the child's family. Sometimes these disagreements occur between members of the same family. I submit that such debate has no place in the modern medical handling of leukemia. The treatments demand the

closest participation and cooperation by the patient and the patient's family. The enemy is a rather complex one: the blood, the bone marrow.

The fear of cancer's destructive potential and forms of destruction is great and founded in reality. The illness and body changes wrought by the medication are tolerated because of promised remissions and hope for cure. These things cannot be handled without trust. Trust must be established. We believe it can only be established and maintained over the necessary months and years by the physician's forming an alliance with the patient and the patient's family. In our current society, this alliance must have at its foundation the sharing of knowledge to the limits of the ability of the patient and his or her family. Children of all ages use the information given them, ranging from the label for the disease and labels for the procedures to the details of the protocols, as intellectual supports in their attempting to cope with the illness and consequent loss of control. The parents and siblings do the same. Such sharing of knowledge even to the point of becoming "experts" in the protocols and treatments helps provide a necessary illusion of control similar to that used by the medical profession.

Thus, disguising the diagnosis has never, in my experience and that of my colleagues, proved helpful to any of the concerned parties. This position does not call for assaulting the patient or his family with the diagnosis or its implications. We share the label for the illness, an explanation of how we know what the diagnosis is and give a description of its implications for the period of treatment and remission period. For the child both the descriptions of how we know what the diagnosis is and discussion of its implications and the treatment are tailored to his age and educational level.

The Initial Period of Adjustment

Initially, information is not elaborately presented. We have learned that both because of feeling unwell and because of tension and fearful expectation little information is retained by the patient or his family from the first meeting in which information is shared concerning the diagnosis, treatment, and course of the disease. All involved are in the process of adjusting to the transition of seeing a previously well self or well child suddenly transformed into a seriously ill self or child. All involved need to develop new techniques of problem solving in this new situation. All need to deal with feelings of helplessness, confusion, and anger. All need to come to terms with ways of evaluating their new reality and within its context learn how to reduce tension, control anger, helplessness, and fear. "Family equilibrium is endangered. Coping strategies and adaptive mechanisms which were useful in dealing with previous developmental and adaptive tasks are challenged, and resources are tapped that may not have been formerly apparent" (Futterman and Hoffman 1973).

Repeated responsiveness on the part of the medical staff to questions as well as information sharing is required to counteract the rather infinite ability of the mind to conjure up the most frightening fantasies, creating greater stress and challenging most seriously coping abilities. With knowledge that the process will be a chronic one the medical team must head off anticipatory mourning. This is best done before remission is obtained by helping parents deal with anxieties over whether or not remission will be obtained. This is more actively the parents' concern for the first course of treatment than the concern of the young patient. Indeed, children commonly regress during this period. Prepubertal children

take comfort in the closeness and supportive concern of their families. Postpubertal children take similar comfort but are more consciously aware of, sensitive to, and challenged by the observed fear, distress, and anger of parents. Moreover, a certain protective withdrawal from the parents may occur transiently. In retrospect, children of all age groups recall little of this period. The teenage group recalls little affective response to the diagnosis and initial treatments.

Adjustment During Remissions and Relapses

We know relatively little about the adjustment of children during this period. This involves a time span of varying length, usually of years. It has characteristics similar to the "Lazarus syndrome" (Easson 1970): "And he that was dead came forth . . ." (John 11:44). One enters the period after being "saved" almost reborn. Once in full remission there is a partial re-entry into the world so abruptly left behind—of school, peers, and activities. Yet, no individual patient can be given a prediction as to how long the remission will last for him. We do know that it is when the first relapse occurs that at least the adolescent patients for the first time consciously struggle with and are overwhelmed transiently with the deadly implications of their disease and the tough game they and their medical team are playing with the treatments. We know basically that they cope—they cope extraordinarily well. Among these patients we encounter fewer episodes of dysfunction due to mental health problems than might be expected in a population of children of the same ages chosen at random. This does not mean we do not see transient depression, anger episodes, withdrawal. But almost always

they are short lived, the children and young people showing a remarkable courage, ability to talk about their disease and its side effects when such talk is appropriate or requested, and an amazing ability to tolerate pain and uncertainty.

For the parents and siblings this is a period during which they must consolidate their adjustment to the altered state of their loved one, a state of chronic uncertainty disguised by the happy, high periods of full remission. In most situations the mothers become very familiar with the treatment regimens and protocols because they bear the primary responsibility for bringing the children to clinic and taking them home. Fathers, for a mixture of reasons ranging from economic to cultural role expectations, are infrequently present and thus develop a different sense of the disease and treatment process, a sense which provides an experiential distance between them and their wives. This relative uninvolvement of most fathers only changes at times of crisis or at the time of death. It is one area which needs great attention. (Paternal involvement as a problem is not something unique to leukemia. It presents a particular challenge in situations where children have chronic disorders.) Parents must cope with overprotective impulses and try to establish a balance between the increased but never stable real need for dependency and the desirability of encouraging the children to function as much as possible as they did before their illness. This thus becomes one of the major re-entry problems for the parents.

The siblings themselves are an important component of the family who have received relatively little attention in this context. We do know that there are reactions, often dramatic, on the part of siblings to the illness in their brother or sister. These reactions include psychophysiologic prob-

lems such as headaches and abdominal pains as well as regressive symptoms such as eneuresis, school phobia, and poor performance in school (Binger 1973). Approximately half, according to the study by Binger, show problems in coping. It is our experience and that of others that these are transient problems which at least in terms of their gross manifestations usually disappear without professional intervention. Another dimension of the healthy siblings' world is anger at the medical center staff for intruding on and partly taking over their lives. This anger seems to exist in all siblings living at home. Such anger has been found in some siblings several years after the onset of treatment. We presently know nothing about the handling and resolution of this anger or of its effects, if any, on the development of the healthy siblings.

For the young patient himself the long period following the first remission varies greatly on the basis of the kind of family the child comes from, the kind of community and school, the kinds of existing problems, and of course his age. Our approach is to encourage as much independence and self-sufficiency as possible. This includes encouraging the adolescent to come to the clinic himself if he is able or at least to stay there without the presence of a parent. We encourage him to return to all his activities. We strongly discourage home tutoring, and make every effort to get the child back to school. We encourage children to relate to friends, relatives, and neighbors as they always did. Re-entry for these children is always challenging. Many of them have lost hair and must wear wigs. Many of them have changed physically because of water retention due to the steroid treatments. Those for whom physical appearance and physical beauty was a major source of pride are seriously challenged. Those for whom thinking, reading,

and other intellectual activity was important are also challenged because they find periods when their minds are not quite working the way they did before—slower and less clearly. This is a highly important area for investigation since we have not sorted out how much of the changes in cognitive functioning and the irregularity of these changes in any one individual are due to medications, to the disease process, to anxiety and depression. Children of all ages need assistance with the developing explanations to friends, teachers, relatives, and others. They seem to cope well with the occasional cruelties and insensitivities. We believe they cope by a well-developed use of denial mechanisms. The kinds of things they encounter range from the obvious of being teased about wigs and being asked questions about their lack of hair or puffy faces, to overt forms of prejudice such as a neighborhood uniting to prevent the purchase of a house once it was discovered that one of the children of the purchasers had leukemia. More subtle challenges are the insensitivities of teachers who ignore requests by the children to share, usually through essays, some of their experience.

Life Planning

This is an area which has received much too little attention. It raises in detail the questions: How does the leukemic child or youth relate to school; how can he/she develop the increasing independence which is part of growing up; how can he/she experience the different stages of intimacy that his/her peers move through; and, when old enough, if he/she survives that long, what about employment and marriage? Concerning school, our position is that the children be encouraged to return to the same school they attended prior to their illness. As part of this procedure, brief and

accurate sharing of information is necessary with the school principal and health officials as well as with the teachers.

This information should be the bare minimum. It should include: (1) the diagnosis; (2) that the child is in remission; (3) that the child will have to miss school periodically for treatments; (4) clear definition of limitations on activities; (5) clear definition of areas in which no limitations are necessary. Beyond this, school personnel should be encouraged to ask questions, to which straight-forward responses should be given. It should be expected that there will be various expressions of anxiety on the part of school personnel; such responses must be handled according to the situation. Usually the parents are the ones who communicate the above information. I raise the question as to whether for an illness like leukemia a member of the medical team should share this responsibility with the parents.

The degree of independence and how to encourage it in the child depends obviously upon the child's age, previous interests, and family style. We have never encountered a situation in which the parents did not need help in this area and in which the child did not have some struggles concerning dependency and independence. Tied to the independence and dependency question is the kind of change in physique a particular child is experiencing. So far we have found that girls and young women who had been encouraged as they grew to focus on physical appearance undergo the most extreme challenges. From the beginning, these patients need a great deal of help in coping with loss of hair and changes in their features. Similarly, help in this respect is needed by the boy whose athletic prowess was a focal point of pride to himself, his family, and his peers.

Except when on the inpatient service, leukemic children often avoid developing

close relationships with each other. The situation in the inpatient service has been described amply by Joel Vernick in a previous publication (1965). Now, however, most of the patients' time is spent in association with a clinic. Intimacy with peers of the same and opposite sex—if it develops—is in the outside world—the world they came from; a world which they can only partially re-enter. We know relatively little about the problems of intimacy for these children, although many, ranging from age 9 to 18 years, have shared with us the fact that they experience a painful sense of distance and a profound sense of isolation which have little to do with their surface social interactions.

One adolescent patient married a year and a half after her diagnosis and remains in remission. Her husband does not have leukemia. They live with her parents. We really know nothing about the quality of this intimacy or the parameters of her decision to marry. Warned about conception (the drugs used in treatment are teratogenic in animal experiments), she has kept her feelings and those of her husband's concerning conception largely to herself. We have several adolescent patients who are engaged. In one situation the couple are both leukemics. Their form of relating is apparently easier to understand. A moment of thought reminds us we understand little.

Questions concerning employment and schooling have to be faced. We do have young adults, diagnosed in adolescence, who are currently employed. In parallel situations we have young people attending college. We encourage both. In coping with the problems of leukemic students, colleges have had to be flexible in adapting their curriculums to the needs of such students in matters of course loads, partial completion of courses, and school transfer. Employment involves much more difficult

problems. For a variety of practical reasons such as insurance and discomfort with the disease, employers are reluctant to hire leukemic patients. If the young people are in full remission, when seeking their doctors' counsel concerning employment, we find ourselves very much in the same situation as psychiatrists are when asked by young people whether to put on their college application that they have received psychiatric care. In psychiatry we avoid the issue if possible; some have recommended lying. Are we in the same position with diseases like leukemia?

Summary

Acute lymphocytic leukemia is presented as a dramatic model in terms of which the quality of life questions raised by modern medical technology can be examined. I have presented four psychosocial aspects of ALL (only one of the chronic yet fatal diseases). The paper shares recommended approaches to patients and families, highlighting some areas for attention and further investigation as well as illustrating some observations. The aspects not touched upon are numerous. Areas for investigation are exciting. Such areas range from delineating what parts of apparent changes in intellectual functioning result from effects of drugs and what part from the effects of the illness or from anxiety and depression, to studies of the psychological coping processes used by patients and their families. For example, we see, contrary to certain teachings, that denial for people with chronic yet fatal illness is a supreme and necessary form of defense. Perhaps we are wrong. We do know that we have not looked carefully or far enough. The entire question cries for the attention of researchers.

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