Childhood Cancer

Impact on the Family

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Proceedings of a Symposium on The Family and Pediatric Cancer, held January 27–29, 1982, at Downstate Medical Center, Brooklyn, New York

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FOREWORD

The past decade has brought extraordinary gains in the outlook for children stricken with cancer. Though cancer remains a leading cause of death for children and young adults, more victims of childhood cancer today will survive than will die. The therapeutic advances and the optimism they instill have prompted researchers and clinicians to analyze the impact of cancer upon young patients and their families and to devise more effective intervention strategies. Hope and survival, juxtaposed with the continuing high mortality associated with certain forms of the illness, add new challenges to management of the psychosocial aspects of cancer. To respond to these challenges we need research as rigorous as that which continues to make inroads in treating the physical illness.

This specific concern for the needs of children suffering from cancer and their families has paralleled an increasing sensitivity on the part of the medical community and the public at large to the limitations of specialized, high technology health care practices. Among the clearest statements of this point of view was Dr. George L. Engel's 1977 proposal for a new "biopsychosocial" model of medicine. "Medicine's crisis," Engel commented, "stems from the logical inference that since 'disease' is defined in terms of somatic parameters, physicians need not be concerned with psychosocial issues which lie outside medicine's responsibility and authority." Arguing that such a limited sphere of concern is inadequate, Engel suggested that the treatment of illness also requires greater attention to the patient as an individual who lives in a social context; treatment, he said, must take into account psychological, social, and cultural factors as well as complicating biological factors.

The response to this growing awareness has been apparent both in developments within the medical professions and in the activities of the public. Medicine has become increasingly attentive to the psychosocial needs of patients and has begun to recognize the potential contributions of psychiatry and the mental health disci-

plines to general medical care. Among the lay public, we have witnessed a proliferation of self-help and mutual support groups for patients and families, more articulate public advocacy for research and health care programs, and more active "consumerism" targeted toward medical accountability.

Viewed against these recent developments, Childhood Cancer: Impact on the Family is more than a timely volume; the issues it addresses are inevitable and essential facets of our contemporary response to cancer. The onset, diagnosis, course, and outcome of the illness are riddled with questions of crucial importance to family members. Many of these questions--perhaps most obviously, "Why my child?"--are not answerable. Yet for other questions, answers do exist, and Adolph Christ and Kalman Flomenhaft have called on distinguished researchers and clinicians to address issues that formerly might have been considered peripheral to the illness. What, for example, do we know about the psychosocial complications of childhood cancer? What can we do to relieve unwarranted parental guilt? How can we, as parents and family members and health care providers, share the burden of illness suffered by a child? To the first point, Bernard Fox, in his review of research on the relationship of stress to cancer etiology, finds no scientific data to support fears that a parent may have contributed to the onset of the illness. Further, he argues persuasively that causal relationships will not be found between parental behaviors and childhood cancers.

Each section of the volume underscores the opportunities for mental health interventions. Research and empirical practice are demonstrating that these interventions can help families cope with the severe psychosocial stresses associated with cancer in a child. The sources of stress are diverse and sometimes unsuspected. Denis Miller notes that lifesaving clinical research protocols frequently entail novel stressors--e.g., informed consent forms--for which strategies are needed to aid patients, parents, and physicians. Grace Christ and Margaret Adams describe in detail specific high stress points that emerge during the course of illness--from the time of initial diagnosis and induction of treatment to re-entry into normal living or termination of treatment and, sometimes, impending death. The authors describe how an understanding of the psychosocial strengths and vulnerabilities of families facilitates the design of techniques. And, as Flomenhaft notes, an appreciation of a family's cultural context is also essential in tailoring psychosocial interventions and enhancing the usefulness of treatments.

While Ida Martinson and colleagues and Jan van Eys show that we are learning much about how to care most effectively and sensitively for the terminally ill child, Gerald Koocher illustrates the continuing need for information useful to the children who

survive the ordeal of cancer. He reports that approximately half of a group of long term survivors showed psychosocial scars years after the completion of treatment. The clear need for new intervention strategies for survivors is further evident in the papers by Adolph Christ and Mark Press which consider the complex, and little understood, cognitive and neuropsychological changes associated with cancer treatment that may not manfiest themselves until years later.

Childhood Cancer: Impact on the Family is an important contribution to the medical literature. It is an equally important contribution to our evolving perceptions of illness and health and the direct relationship of the family--both as a social institution and a clinical entity--to either of these states. Yet perhaps the greatest contribution of this book is its implicit call for continued broad research into the medical and psychosocial aspects of cancer. Successful collaborations between such organizations as the National Cancer Institute and the American Cancer Society, and countless individual researchers and clinicians, have made possible dramatic progress in our ability to treat childhood cancer. Such collaboration must continue and must involve an even wider cast of characters representing basic and clinical research in the medical and mental health sciences.

The battle against childhood cancer is being fought and won by dedicated and outstanding scientists and clinicians. But the real heroes are the children and their families who, often in ways that we cannot yet understand, are giving their lives to the cause. We owe a debt to them, a debt that can be acknowledged only through a continuation of our efforts and our learning.

Herbert Pardes, M.D.
Director
National Institute of Mental Health

PREFACE

Childhood malignancies are now less considered terminal than chronic life-threatening diseases. New treatments have greatly improved survival rates. The challenge facing us now is addressing the quality of the life of the survivors. Children may require years of care and treatment with toxic, debilitating and painful side effects. Clearly, the family has a major role in the ongoing treatment and care of the child, and all family members in turn are significantly affected by having one member ill with cancer.

To consider the emotional and social stresses and practical interventions with families having children with cancer, the Elizabeth Berliss Saenger, M.D. Memorial Fund generously supported the symposium on "Childhood Cancer: Impact on Family." A group of specialists convened at Downstate Medical Center in January, 1982 to address a number of issues including: What are the stresses and decisions for the family and the treatment team posed by recent advances and strategies in cancer treatment? What is the impact of research treatments? Do psychosocial interventions with parents and siblings during the early stages of cancer prevent subsequent marital and family problems? What coping strategies are used by family members with adolescent patients with different cancers? What are the effects on the families of children dying at home or in the hospital? What is the current research status of the psychogenic etiology of cancer?

The contributions to the symposium were thoughtful, sensitive and scholarly. The life and death struggles of the child, and how they affect the family and professionals were forthrightly discussed. At the end of the two days, it appeared that the participants had had a profound intellectual and emotional experience.

The organization and conduct of the symposium and compilation of the proceedings were made possible by the unstinting efforts of Ms. Beverley DeSouza, Mr. Martin Nathanson, Ms. Jeaneen Simonelli and Mrs. Saundra Bogen. We would like to thank Robert Dickes, M.D.

who, as Chairman of the Department of Psychiatry, originally encouraged the development of this series of symposia. Finally, we want to acknowledge the encouragement and support of our families in this vital endeavor.

Adolph E. Christ, M.D.

Kalman Flomenhaft, Ph.D.

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INTRODUCTION: PSYCHOSOCIAL CHALLENGES IN CHILDHOOD CANCER

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There are three challenges that children and adolescents with cancer present to the mental health and oncology professions, challenges that prompted us to invite a panel of distinguished contributors to this third symposium on family therapy.

The first challenge is to develop ever more effective and precise methods of psychosocial interventions to enhance the adaptation of the patient and his family to these serious illnesses. A number of the discussants will address this issue, including a discussion of different techniques that are applicable during various stages of the illness, the importance of intervention during the first days and weeks of the illness, the long range effect of the illness and its treatment on the children, their siblings and parents.

A second challenge is to continue the development of a theoretical model that will aid us in understanding the responses of emotionally normal children and families to severe protracted life threatening stress. Individual and family psychiatric theory have come a long way in understanding chronic emotional disturbance and the adaptive and maladaptive reactions of emotionally disturbed individuals and families to stress. We have also amassed an impressive amount of information about normal development, and have learned to use these insights in explaining normal and psychopathological patients. We have surprisingly little information about the parameters of "normal" and "pathological" emotional responses of otherwise emotionally healthy children and their families to chronic severe stress, a state characteristic of the patient with cancer.

The study of these emotionally normal stressed individuals will help us understand in a unique way the importance of the interaction of the healthy defenses, the adaptation-enhancing interaction of the "normal" ego, superego, and ego-ideal in the face of chronic stress, the interaction of "normal" intrapsychic and interpersonal factors in the development of coping strategies under circumstances of chronic life threatening stress.

The third challenge is of a different nature: cancer and its threat to life allows heroic measures to be used and explored in the course of its treatment, measures that in themselves are not as free of risk to the viability and vitality of the organism and to specific organs as one would ideally like. Specifically, some of these treatments adversely affect the central nervous system (CNS). A major emerging thrust in psychiatric thinking is an effort to understand the interaction of mind-brain-psyche. The careful long term evaluation of children treated with drugs and radiation suspected of adversely affecting the brain would facilitate the further exploration of this interaction.

Especially with children whose brain functioning is intact prior to the treatment, and where the disease itself may have minimal or no effect on the CNS, a careful study of the specific CNS effects of the treatment, with special emphasis on the correlation of altered function to structural change would be invaluable in elucidating this type of neuropsychological correlations. The full effect of the CNS damage even with a developing child may not be manifest for a number of years, and the impact of this on the ongoing developmental processes of the child may require a great many years to ascertain in any given individual. What is unique, and represents a particular challenge, however, is that these youngsters can and should be carefully evaluated BEFORE the required treatment is given, in order to determine the proportion of the etiology of behavioral alteration that is caused by the CNS damage. The countertransference reactions that need to be overcome before the study of iatrogenically caused CNS damage can be carefully done may be insuperable, but that is part of the third challenge.

The contributors to this book represent a variety of practitioners, medical and psychosocial, whose continuing collaboration is essential to optimize the provision of available care, and to enlarge the horizons of our respective disciplines to meet those challenges posed by the cancer patients and their families.

PSYCHOGENIC ETIOLOGY AND PROGNOSIS OF CANCER--CURRENT STATUS OF THEORY

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INTRODUCTION

During the last five or ten years, there has been much interest in regard to two speculations: first, that certain personality features tend to predispose people to cancer or that stress can induce or predispose to cancer; and second, that among those who already have the disease, personality or stress can affect its progress or indeed affect survival time. Scientists have been looking at these questions for a long time. Three answers have appeared for both human and animal studies. The first is, "Yes, this, that or the other stressful event or personality feature does affect the appearance or progress of cancer." The second is "No, it doesn't." The third is, "We really don't know because the studies that were done were poorly designed and we can't draw secure conclusions from flawed studies, some badly flawed." There is a large question mark in regard to the animal characteristics question, mostly because that issue was really not pursued to any degree. After all, who would ask about "personality" of mice in relation to cancer susceptibility?

Since the earlier studies, however, our understanding of interrelationships among those things that might affect the above answers has increased considerably, and we may be in a better position to express some probabilities in these matters even though we cannot express certainties about them. In the following discussion, I will look at some of the "Yes's", "No's" and "We really don't know's."

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EVIDENCE WITHOUT REFERENCE TO MECHANISMS

Positive Evidence

This section deals with reports of a positive relationship between psychosocial factors (PF) and risk or progress of cancer. The term "PF" will include psychological factors such as stress (here meaning internal effect of an external stressful event), but will not include psychological or social factors that cause behavior leading to cancer such as smoking or occupation. Elsewhere I have referred to PF as endogenous psychosocial factors and to the excluded factors as exogenous (Fox, 1982a). Levy (1981) has called them direct and indirect factors, respectively.

A number of reviews have appeared, citing mostly studies showing positive relationships and paying relatively little critical attention to problems of analysis, design and potential bias. Examples of these are reports by Achterberg et al. (1976), Aimez (1972), Bahnson (1976), Baltrusch (1963, 1964a, 1964b, 1975), Cagossi (1971), Headley (1977), LeShan (1959), Meerwein (1980), and Simmons (1966). Several others have examined the general literature more critically. They include Abse (1974), Sklar and Anisman (1981), Bahnson (1966), Bahnson and Kissen (1969), Crisp (1970), Fox (1978, 1982b), Holden (1978), McCoy (1976), Morrison and Paffenbarger (1981), Perrin and Pierce (1959), and Wirsching (1979). Of all the reviews, Baltrusch's were the most comprehensive, although they were mostly uncritical reports of findings.

A considerable number of psychosocial factors have been said to be related to the presence, risk or prognosis of cancer. Some examples are given by Abse (1974): denial and repression (7 references); impaired self-awareness and introspective capacity (5 references); poor outlet for emotional discharge (7 references); diminished expression of aggression (5 references); self-sacrificing and self-blaming (6 references); rigid, conventional (5 references); a "reality" orientation (6 references); meager but deeply felt object cathexes (3 references); and (predisposition for experiencing) hopelessness and despair (4 references). Other dimensions and influencers of the psyche have been reported from time to time: closeness to parents (Thomas, 1976; Thomas et al., 1972); excessive expression of aggression (Greer et al., 1979); body image constriction (Harrower et al., 1975; Fisher and Cleveland, 1956); adverse childhood events (LeShan, 1959); adverse adult events (Kissen, 1966); diminished sexuality (Rotkin, 1973); depression (several writers, e.g., Shekelle et al., 1981); interval between birth of cancer patient and adjacent sibling (Reznikoff, 1955). Many others have been reported. A special case is the claimed deficiency in the cancer mortality of psychotics, especially schizophrenics (for critiques see duPan and Muller, 1977 and Fox, 1978).

In the animal area, it is enough merely to make the brief statement that stress has unequivocally been shown both to increase growth of implanted tumors and hasten the appearance of spontaneous tumors (Riley, 1981). There is no doubt of that generalization. Moreover, it is quite certain that different genetic strains of animals are differentially susceptible to growth of implants and to appearance of spontaneous tumors (Sklar and Anisman, 1981; Newberry, 1981; Riley, 1976). There is almost no evidence, however, that animals with different behavioral patterns (other than those brought about by hormonal changes or circumstantial changes like moving a mouse to another mouse family cage) show similar differences. One might be able to show that different strains displayed different behavior patterns, and to that extent might be said to show a relationship between behavior and cancer susceptibility. But that has not been the focus of much inquiry. (But see Sklar and Anisman's remarks on aggressiveness [1981] and Fox's mention of conditionability in the early Russian research [1981, p. 128]).

Negative Evidence

In the human, a number of studies have yielded results showing no differences between cancer patients and others, between those destined to get cancer and others, and between patients surviving a longer and shorter time, in regard to many PF. Included in such studies are those showing results for a PF opposite to one giving positive results in the section above. The most frequently reported negative result is that relating to traumatic life events such as divorce, death, job loss, etc. For example, a number of workers found no difference in stressful life events among patients and nonpatients: e.g., Greer and Morris (1975); Finn et al. (1974); Grissom et al. (1975); Graham et al. (1971); Snell and Graham (1971); Muslin and Pieper (1962). Another case is extroversion. For example, Kissen and Eysenck (1962) found lung cancer patients as opposed to others, to be more extroverted, using Eysenck's MPI (Maudsley Personality Inventory), while Berndt et al. (1980), using the same instrument, found that cancer patients did not generally differ from controls. Other negative results were those of Keehn et al. (1974), who found that those discharged for psychoneuroticism in World War II, when followed up, showed no excess of cancer during the following 24 years over those not so discharged. In a parallel study, Keehn (1980) showed no excess cancer among prisoners of war in any of the three most recent war theaters: World War II, Asian theater and European theater, and Korean conflict theater. Shekelle et al. failed to find differences in denial and repression (1981) in the same groups that showed a difference in depression (1981). Schmale and Iker reported no difference in MMPI (Minnesota Multiphasic Personality Inventory) in cancer patients and noncancer patients among a group of women with severe cervical dysplasia (1966). Fox et al. (1978) found no difference in MMPI scores among

melanoma patients who later relapsed within a year after surgery and those who did not relapse. Duszynski et al. (1981) found a slight trend but no significant differences between cancer cases and controls in respect to four childhood events: parental death, parental divorce, sibling death, and having been the youngest child for less than two years. Many positive and negative studies can be cited. The point is that in many cases, for similar variables, one can find both "yes" and "no" answers.

Negative animal data also abound. Several major reviews describe many conditions under which stress will either reduce susceptibility to cancer or delay and even prevent the "take" of an implanted tumor (LaBarba, 1970; Newberry, 1980; Riley, 1981; Sklar and Anisman, 1981). Such effects are attributed to a number of potential causes, most of them reasonable speculations. In most cases, however, the actual causes have yet to be pinned down. In addition to the cases where stress reduces risk or progress of cancer, some studies show no effect at all under various conditions.

THEORETICAL ISSUES REGARDING PSYCHOGENIC ETIOLOGY OF CANCER

At this point, let us divide PF into the two types mentioned above: those relating to etiology of cancer and those relating to prognosis among people who already have the disease. This must be done because the theoretical issues involved in making a judgment are different in the two cases. First, the issue of psychogenic etiology of cancer will be addressed.

Genetic Sources of Cancer

Genes certainly influence the occurrence of cancer. The findings in the animal literature show wide differences in cancer susceptibilities among animal strains, but most research animals are of a special type. Laboratory stock has been bred to pure strains in respect to particular selective characteristics, with 30 or more brother-sister matings. This is not true of humans, although different ethnic groups can be identified with different basic incidences of cancer. For example, there is a possible excess of naso-pharyngeal cancer among southern Chinese (Simons et al., 1975), and it has been reported that people with type A blood have a greater risk of certain cancers than those with type O (King and Petrakis, 1977), although those findings have been severely attacked (Wiener, 1970). One can reason that if certain PF of genetic origin, say "A", are related to other genetic characteristics tending to high or low cancer risk, say "B", people with A will tend to have a high or low cancer risk, depending on how closely A and B are related. In that way, a certain percentage of the population, those with A, might be at higher or lower risk than those without A. This gives us a mechanism for explaining some of the positive

relationships described above.

First, a caution. The basis for a possible genetic effect of a PF is a known association with a genetic cancer risk. So far, no such connection has been made between a PF and a genetic source of cancer risk. Indeed, the association between single genetic traits in general and cancer risk in humans has really been verified only in cases of quite high risk, such as cancer-prone families or those with rare genetic diseases. On the other hand, estimates of the ultimate number of single-gene cancer-related traits that might be discovered have been made. Lynch, for example (1980), suggests 5-10 percent of all cancers. We have not yet verified the proportion of cancer cases associated with multiple-gene inheritance, but research is going forward. Lynch has also made an estimate for the multiple-gene case--10-15 percent (1980). As an aside, with one or two exceptions, the data show that clear ethnic differences in the shape of the cancer curve of incidence versus age appear in the young (Miller, 1977), as is the case with most cancers known to be associated with single genes.

One must draw conclusions cautiously, however. The general idea of cancer appearing in successive stages of genetic transformation, that is, mutation, (Knudson, 1977) has been well received. It suggests that at least two "hits", that is, two such transformations, on a cell are necessary for a cancer to appear, provided the hits are directly related to the transformation to cancer and not to other cell changes. For such cancers Knudson's theory is quite consistent with the observation of initiator-promoter relationships. An initiator tends to produce a permanent genetic change in a cell, but not cancer. According to Moolgavkar and Knudson (1981), a promoter, which does not create cancer in normal cells by itself (although a stimulus can be both an initiator and promoter), increases the chances of a second hit effecting a cancerous change by promoting growth of cells. If those cells are ones already hit once, the odds of a second hit on at least one of them increase considerably. The theory is that when the first cellular change, corresponding to initiation, comes as a genetic one, it has appeared at conception, rather than on exposure to a cancer-causing agent some time during the person's development to adulthood and old age. The risk, therefore, of a second hit attacking a changed cell and producing cancer arises much earlier in the person's life history.

From that position, if any PF were associated with any "first hits" they would tend to show up in early cancers--children's and young adults'. Lynch (1980, p. 233) notes that the proportion of genetic cancers is substantially greater in people below age 40 than those above. But we should also note that the proportion of all cancer diagnoses below age 40 in the U.S.A. is still only 7 percent (SEER, 1981). It is probably not more than 10 percent in most developed countries, even those with low overall cancer rates.

Moreover, a substantial proportion of early cancers have nothing to do with genetics, but are the result of two successive hits by chance. Such events are fully to be expected. Thus, if present at all, the possible contribution of PF via direct genetic sources of cancer, low overall, must be considerably lower when one considers, first of all, that specific PF must correlate well with genetic traits manifested as first hits in order for them to have any reasonable association of genetic cancer proneness based on Knudson's "hits" concept. Secondly, all nongenetic cancers occurring by chance must be subtracted from the total before counting the genetic ones.

Genetic PF might also contribute to cancer risk, both increasing and decreasing it, through the availability of enzymes. Many types are known, with different functions. Among these is the function of transforming carcinogens and carcinogenic products of noncarcinogens to harmless substances. Some enzymes do the reverse --change harmless substances to carcinogens. When these enzymes are under genetic control, risk of exposure to carcinogens can increase or decrease. A second function of enzymes is control of DNA repair after damage by chemical, radiation, virus, or other causes. It is known that there are at least eight different complementation groups involved in the disease xeroderma pigmentosum. If any one of these is deficient, the disease appears. These enzymes are all part of the DNA repair process. One removes the faulty DNA section, another copies a correct version of the removed section, one replaces it, etc. (Lehmann, 1979). It is also known (e.g., Agarwal et al., 1977) that faulty DNA repair appears in other tissue than skin. It is of interest that in the test by these authors of damage to repair function of lymphocytes of 12 normals, 11 showed characteristic reduction of repair capability after varying degrees of in vitro X-ray dosage, but one showed much less damage, suggesting that this person's lymphocytes "were uniquely resistant to X-irradiation." If this were a genetic phenomenon, and in addition, if that trait was related to some PF, the latter could be protective against one source of carcinogenesis in one tissue. These eight complementation groups can be regarded as eight different genotypes for that disease. "In the case of gastrointestinal tract cancer, there are believed to be at least 15..., and in breast cancer 7..., cancer-prone genotypes, respectively..." (Lynch, 1980, p. 238). If this is true, then in respect to a possible correspondence between PF and genotypes at high or low risk for cancer, one might expect many, or several, genotypes for other cancers. Now the probability that there is a match between genotype and PF genotype becomes much smaller, since instead of there being a hundred different kinds of cancer, there are probably hundreds. The upshot for research is that it would be far more difficult to discover a correspondence of cancer, even a single kind, with a genetically based PF, than might be the case if there were only one genotype per cancer site. Hypo-

theses about the proneness of people with certain inborn personality types to get cancer would be almost impossible to test, and results purporting to show such a thing are even now subject to considerable question.

Genetic tendency to produce hormones in different proportions could affect proneness to cancer, since it is quite clear that hormonal activity influences cancer susceptibility, e.g., by affecting the metabolic destruction of carcinogens (Bakshi et al., 1977). But this avenue of research is almost impossible to address because hormonal concentrations are so strongly influenced by ambient events such as diet (Weisburger et al., 1977). Nevertheless, it might be of interest to ask the present question about cancer patients examined by Wakisaka et al. (1972) who found differences in balding patterns of age among stomach cancer patients and controls, as well as differences in hormonal patterns.

Last, are there differences in immune response associated with genetic origins that could be applied to the population at large? We already know that immune deficiency diseases, though rare, quite clearly demonstrate increases in cancer risk ranging from two to three up to 10,000. The question is whether genetic immune processes are more broadly implicated in cancer susceptibility. It is likely, but we are not yet at the point of a secure position. Gatti (1977) points out that while the HLA-A or B loci of the major histocompatibility complex in man have been judged to have little influence on cancer (Terasaki et al., 1977), theory points to the HLA-D locus as a likely point of departure. We have only fragmentary data on this issue, however. Surely, if we know little about the genetics of immune response, and we know practically nothing about the genetics of PF, one cannot talk about the combination with any confidence, but one can speculate.

The one place where a genetic connection could affect a meaningful part of the population is an immune response covering resistance to cancer at many sites. In an interesting finding, Locke et al. (1979) observed low levels of natural killer (NK) cells among poorly coping students with many life stress events, and higher levels among those who coped well. NK cells, known to be activated by interferon, seem to recognize and attack certain cancer cells in spite of low or absent surface antigens, measured with current techniques (Herberman and Holden, 1979). If coping or some heritable PF were found to be related to NK level, and if NK level were found to be related to cancer incidence, we would have a first real connection. It would be worth pursuing a second finding by Locke et al. (1978), showing the low NK group to have uniformly (except for one test) lower scores on the MMPI scales than the high NK group. If Gottesman's claims (1969) of heritable elements in MMPI scores can be validated, and the findings of Locke's group are correct, we would have a first connection between a genetic PF and

mechanism related to cancer risk. The NK connection to cancer incidence in the human has not yet been made. This is an important statement because in animals Herberman and Holden (1979) were not able to show that mouse strains with low NK activity to individual tumor cell lines were uniformly nonreactive to other cell lines. They were reactive to only one tumor cell line. If this is true in the human, then we have the same heterogeneous situation as before, and the chance of an identifiable connection drops radically. In an actual experiment, a retrospective study might show results but the proportions at risk would be divided up into tiny moieties made up of different cancer sites.

In evaluating the above findings about genetics, we must be aware of the constraints put on our conclusions by several matters. The first is identification of genetically controlled PF. While the literature makes claims in that direction (e.g., Manesovitz et al., 1969), the measures yielding positive results were usually not the same ones used in describing reported cancer-related PF--e.g., Cattell's "tough-minded versus tender-minded" (1965), Scarr's activity and motivation (1966), and Schaffer and Emerson's social attachment (1964). A few exceptions exist, like Gottesman's MMPI results (1969). Second, there is the problem of reliability and validity of PF measures. No one has estimated confidence bounds on the cancer-incidence and PF relationship based on the reliabilities of the PF measures.

I do not claim that PF genotypes connected to cancer-enhancing or cancer-protective genotypes do not exist; I claim that the connection has not been demonstrated and with our present knowledge cannot be demonstrated. Some predictions can be made from the above, however. First, if a connection were made, one would expect the expression of the PF indicating increased risk to appear in young persons, and that indicating lower risk to manifest itself throughout the lifetime of the phenotype. Second, one would expect the connection to be specific for particular cancer sites. Finally, one could conceive that a PF may not actually trigger a cancer, but may merely cause an advance in time for an event whose probability is high to begin with.

Stress

It has been clearly shown that stress in animals can hasten the onset of viral cancer that is expected later in the animal's life (Riley, 1976). It is also clear that stress in animals can increase the carcinogenic potential of various other mutagens--radiation, chemicals--that would otherwise be protected against (Sklar and Anisman, 1981). But similarly, stress can delay or decrease that same carcinogenic potential (Newberry, 1981). Moreover, the nature of stress is not always clear. For example, Sklar and Anisman

(1979) showed that in yoked mice, control or anticipation of a stressor gave a lower tumor yield than having no knowledge about the arrival of the stressor. Yet Newberry (1981) reported that while he duplicated the results in principle for mice, no such difference in tumor yield appeared when the experimental animal was the rat. Stress is said to act mostly through hormonal effects, but can also act through metabolic and direct psychoneural effect on the immune system (IS) (Ader, 1981). The literature shows a wide variety of cancer-protective and cancer-enhancing effects of stress, depending on many variables--time, duration, type, intensity, intermittency, frequency, number, etc., of stressors; and strain, age, sex, prior handling, cage mates, behavior, diet, existing viral invasion, parity, housing, etc., of animals (Newberry, 1981; Riley, 1981; Sklar and Anisman, 1981).

The most frequently cited source of effect on cancer susceptibility is the IS (Riley, 1981, Solomon and Amkraut, 1981). It is supposed to be affected by proliferation of ACTH, which stimulates adrenal corticoid secretion, which is believed to depress the anticancer activity of the IS, especially T-cells. But if the hormone diminishes activity of suppressor cells more than that of other IS cells, it may enhance tumor-killing because suppressor cells do just that--suppress immune activity of certain IS cells, but, it is believed, for a different original biological reason than cancer defense.

It is dangerous to draw facile conclusions about the human from animal experiments. Some pertinent differences between human and animal experiments are presented.

1. Rodent strains have been bred for special characteristics, often for heightened cancer susceptibility. The human population is highly outbred. Among various animal strains, many internal phenomena may differ, e.g., hormones, enzymes, fat level, metabolism.

2. A large number of spontaneous cancers in animals are viral, whereas only two to three percent of all human cancers in the U.S.A. are viral, based on our present knowledge. Another percent or so may be shown to be viral among the leukemias. Viral tumors tend to express antigens clearly, becoming prime targets for immune response and therefore less easily dealt with if the IS is depressed.

3. Most stress experiments on animals involve tumor transplants (not relevant to this section on etiology), large doses of carcinogens, or strong treatment with X-rays. These, for the most part, yield tumors with strong antigens that are easily detectable by the IS. Not so in the human, where, except for the chance X-ray,

cosmic ray, nuclear emission or genetic cases, carcinogenic processes seem to be slow, insidious, drawn-out processes, and often antigenicity is low. Examples of tumors with long induction times to malignancy are breast, colon, lung, prostate, stomach, and tobacco-related oral cancer. The first five of these cover fully half of all cancers in the U.S.A.

4. Rodents are much more responsive to corticosteroids, the hormones felt to be most involved in stress-induced immune suppression, than humans are (Claman, 1972).

5. When rodents are immunosuppressed they get tumors without restriction on site except for that imposed by their strain specificity and the type of virus (e.g., Bittner virus produces mammary cancers). When humans are immunosuppressed the majority of the tumors are lymphoreticular, that is, elements of the IS itself become malignant. There is a slight excess of risk for other tumors, but not nearly so much as for the IS, especially reticulum cell sarcoma, whose incidence in the immunosuppressed patient is 150 times that of the age, sex and race-matched population (Hoover, 1977).

6. Since different strains are at varying risk for different kinds of tumors, the effects of stress will interact with the baseline susceptibility. I predict that stress would exert less influence on low-risk animals than on high-risk. Extrapolation to the human in general would be subject to wide variation, therefore, depending on the risk category of the experimental animal and the particular human being examined (assuming my hypothesis to be correct).

7. In the human it is quite clear that repair of ultraviolet-induced damage to DNA in the skin is more efficient than in short-lived animals. If this is true for other tissue (see Agarwal, 1977) and all other things are equal, including relative stress level, this implies that in man the IS gives a smaller contribution to total cancer protection than in animals, since a larger proportion is contributed in man by DNA repair. The evidence is as follows: Peto (1977) pointed out that the relative risk of cancer in man grows as the fourth or fifth power of age. If the human has 1000 times the number of cells as the mouse, he said, and lives 30 times as long, he should have (30^{4+} = 1,000,000) x 1000 = 1,000,000,000 times the probability of getting cancer as the mouse. Instead, for varying strains, man's expectancy of cancer differs by no more than two or three times that of the mouse. We know that the mouse's skin repair capabilities are lower than man's. Hart and Setlow (1974) did the very experiment to test this question, measuring repair in vitro after damage to equivalent skin cells by ultraviolet rays (UV) in tissue from man, elephant, cow, hamster, rat, mouse, and shrew. Repair capability was a linear function of log of longevity

of the species for all UV levels. While DNA repair might not explain fully the discrepancy between Peto's expected probability for man and mouse, it explains it partially. If IS in man is less important overall in protection from cancer than in mouse, we should be careful in using animal experiments to make estimates of the role of stress and IS function related to it in carcinogenesis.

While the points of contrast mentioned above tell us to be cautious about drawing confident conclusions about man from animal work, there are still fundamental likenesses among most mammalian carcinogenic processes arising from similar causes, and among their IS's. The likenesses are more important overall than the differences. One can compare them to the roots of a language, and the differences to inflectional changes.

1. Cancers are induced by the same mechanisms, by and large, in man and other animals. They involve mutagenic, quasi-mutagenic and epigenetic changes in the cell.

2. Except for special cases, malignancies are believed to arise from a single cell in all organisms. All that we know points to the fact that, within a matrix of environmental and genetic predispositions, transformation of that cell to malignancy is a matter of chance. The case of the extremely high carcinogenic dose is a trivial extreme.

3. The more inbred a line is, up to a functionally asymptotic state, the more clearly is the level of cancer susceptibility manifested, both in man and other animals.

4. All the processes and structures involved in susceptibility to and protection against cancer are found in animals and man: carcinogen-processing enzymes; DNA repair mechanisms; basic activity level and abundance of various IS elements; and tendency to produce various hormones under stress or other circumstances.

5. Of those chemicals found to be carcinogenic in man, some 90% are also carcinogenic in some other mammals.

6. Carcinogens do the same things in man that they do in animals--insert themselves into DNA strands, break them, prevent repair or reduce its rate, polymerize DNA bases, etc.

7. Stress in man, for hormones that have been tested, provokes the same hormonal responses that have been observed in animals, with quantitative differences.

8. Within limits, hormones do the same things to the human IS as they do to the animal's.

9. The overall epidemiology of animals' cancers, for equal etiologies, and the classes of etiology themselves, are broadly comparable as to type and rate, and conceptually quite comparable in mechanism.

In regard to human studies on stress and cancer, Keehn's data on prisoners of war (1979) and Segal's reported data on concentration camp survivors (1974) are the only studies I know other than those relating to life-stress measures such as the Holmes-Rahe scale (1967). I have already indicated that Keehn's results were negative, and that many more negative than positive results were found for life-stress measures. Segal also reported no differences between survivors and the population at large in cancer mortality.

The above studies deal directly with the initiating variable, stressors, and the final variable, having or dying from cancer. Studies of intermediate processes have also been done: comparison of PF, whether stress-induced or genetic, and immune response. Some of these have been discussed elsewhere (see Fox, 1981; Bartrop et al., 1977; Palmblad et al., 1976; Greene et al., 1978; Locke and Heisel, 1979; Roessler, 1979; and Schleifer et al., 1980). Some findings were positive; that is, a connection was made between IS function and some PF. But that is all these workers showed. It is a necessary first step, but in view of the cautions regarding the variability and inconsistency of animal results, we should look with the same wariness at these, and make no extrapolation yet.

Thus far we have (1) a connection of some kinds between PF and some immune functions; (2) a connection in some studies between some PF and cancer existence; which is cause and which is effect is not known; (3) a connection in a few cases between PF and future cancer; and (4) evidence that IS dysfunction is associated with certain very specific cancers, not characteristic of the distribution of cancers in the population at large. As mentioned above, we can draw no conclusions from 1. Enough has been written about the pitfalls of retrospective studies among cancer patients and the faults of most known prospective ones to leave little confidence in a strong statement about such studies relating PF and cancer in 2. and 3. The relationship of the IS to cancer is undoubted, but its details and ramifications, and their connection to PF, are quite unexplored, and we can only say that such studies provide a possible mechanism for the fundamental set of connections: PF and the IS and cancer. We have no clear evidence that the full set of connections exists, and if it exists, which results appear--protective, carcinogenic or both--for different PF, IS and cancer elements. But there is evidence that makes it very unlikely that the full set of connections exists at all, for certain populations (not individuals). That evidence will be described next.

Demographic Evidence

One can construct a theory saying that large differences in cancer incidence among countries indicate that most carcinogenesis resides in environmental sources. In fact, demographic epidemiologists have done just that. For example, Higginson (1969) takes the position that 80-90 percent of all cancers are environmental, based on the rates found in those countries with the lowest incidence for each cancer. The assumption was that that base rate is constant for all countries, and that any excess resides in added external carcinogenic stimuli.

The PF theorist can claim that PF ride on top of existing environmental carcinogenic conditions, so that, in the absence of an exact amount attributable to the carcinogen, a substantial contribution might come from PF, a good part of which would have to be stress. It is possible, with two lines of argument, to render the stress supposition very unlikely. For the first line, consider the fact that when peoples migrate their cancer rates change and tend toward the new country's rates, reaching those rates or close to them in the second or third generation. One could explain that handily if the rates decreased or increased consistently, in association with the stress of migration. But it would not be likely that the rates would go in both directions at the same time, increasing for some cancers, decreasing for others. Only two possibilities could account for that state of affairs. Either the PF effect was selective for specific cancers, a real possibility but leading to terrible research problems; or the PF effect was either minuscule or nonexistent, and the changes were mostly or all environmentally induced.

For the second, and perhaps the more potent argument, we may assume that in the U.S.A., with increase in local migration, alienation from one's cultural values, transformation to nuclear rather than extended families, mobility, status change, and the other stressors described by psychologists and sociologists in our recently changing society, life stressors would have been increasing over the time of such changes. If there was a substantial trend upward, as would be expected, three things would have happened: Those cancers whose rates rose during the last six decades (allowing 10 years for latent period) would have independently risen (without the PF effects) less than they apparently did; those that fell during this period (e.g., stomach and cervix) would have independently fallen more than they apparently did; and those that stayed constant would have had to fall, independently, precisely enough for the effect of PF to compensate for that fall in order to render the 50-year rate constant. Breast and colon cancers, two of the most frequent of all cancers, are among those remaining constant. PF might be selective, but because there were

so many in the group of essentially constant cancers, other explanations are to me more likely: that stress-related PF have not changed over these 50 years; or that stress has little to do with the incidence rates of cancer.

The Implications of Positive and Negative Results

What, then, can one make of the many positive results described in the first section? A number of difficulties can be found with many of those studies in terms of research design. These merely make one less confident in the studies, but are not cause to reject them out of hand (Fox, 1978; Morrison and Paffenbarger, 1981; Crisp, 1970). It does make it easier, however, to take the position that an unknown number might be rejected.

Further, we can say that an unknown number must be rejected. The total causal contribution of 100% comes from all the carcinogens --hormones, radiation, viruses, chemical carcinogens like smoke or chromium or nitrosamines, hereditary causes, IS dysfunction, and possibly stress and personality, which are presumed to affect the IS or hormones, mostly. In the first section I named 17 different kinds of PF that have been reported to increase risk of cancer. Others (e.g., Hurny and Adler, 1981; Baltrusch, 1975) have reported many more. Say there are 30 such. If they were all independent and equal, no more than about 3% would be attributable to any single one. If we assume that they are not independent, how shall one decide what portions of which ones are common, which ones should be retained for part effect, and which ones thrown out altogether? Now we must add in all the other, that is, the environmental and the nonpsychological genetic, factors. The total that might be attributable to PF then becomes small overall, and that attributable to any single one becomes minute. How is it possible to say, now, that PF #14 is more believable, if real, than PF #27? Replicated findings? Abse (1974) and others have already shown that many PF have yielded positive results in a number of studies each. Mere repetition of a finding, then, cannot be an indicator in this situation.

One might use results of prospective studies as more believable, but few prospective studies have yielded the same positive results as any other, e.g., Shekelle et al. (1981), depression; Thomas (1976), closeness to parents; Hagnell (1976), extraversion; Morrison (1980), mixed psychophysiological factors; Grossarth-Maticek's (1980), mixed psychosocial factors, but including depression;* and McCoy (1974), social introversion. Moreover, no one

*Grossarth-Maticek's results are hard to believe: almost exclusively on the basis of a 109-item psychosocial scale, out of 1353 persons he predicted that 172 would get cancer, of whom 92.4% did; that

has mentioned the fact that whenever one or more variables have yielded positive results, all the other PF tested in the study were negative. No one ever counts those and places them against the far smaller number of occasions on which these same variables yielded positive results in other studies.

One can say that among all the findings, mathematically it must be the case that a number--which, we do not know--are chance results, biased results, or artifactual in some way, assuming that they are all honest results. This state of affairs leaves the researcher in a quandary. If he or she wants to do research to follow up a hypothesis in the literature, which shall it be? If one is a policy maker, or a therapist, which of the results should be trusted? If one wants to make a statement to the public, as a public worker, shall there be any positive pronouncement at all? And if so, which of the many findings should be used?

The conclusion is clear. One cannot trust any of the results cited above merely on the basis of reported findings. The experiments must be carefully reviewed and suspicion of possible bias and unreliability should lead one to put a finding aside, waiting, instead, for studies with rigorous design, replicated again and again. Rigorous design requires contollling for (by matching or statistical analysis) those variables that might affect the outcome, as well as proper sampling.

My position will be, then, that for psychogenic etiology of cancer the case is still wide open, and one cannot in all scientific conscience take a confident position now. At best the present position must be tentative, if not outright speculative.

THEORETICAL ISSUES REGARDING PSYCHOGENIC PROGNOSIS OF CANCER

This topic is somewhat different from the etiology question because the mechanisms involved are more restricted and the findings from therapy and from animal work are much less subject to the qualms described above in regard to extrapolating to PF.

All the studies in which implants are used correspond, in some degree, to the case of the cancer patient who already has a tumor. It doesn't matter (except for a few cases) what the origin of the cancer was--radiation, virus, chemical, hormone, immune deficiency (the last may be one of the cases where it does matter). We find increases of corticosteroids, related to depressed immune function,

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411 would get one of a set of six "internal" diseases, of whom 82.0% did; and that 770 would get neither of those two disease classes, of whom 99.1% did, all during the ten years following scale administration.

far more often than we do enhancement of immune function. The concept by Amkraut and Solomon (1975) of a relatively short time "window" during which immune enhancement can take place associated with a particular treatment is probably applicable to other phenomena associated with immune enhancement (see Riley, 1981). But the bulk of the effects of the environment on the cancer patient is likely to be IS-depressant, not enhancing. A further fact confusing the issue is that both in animals and humans, surgery increases corticosteroid level considerably, also depressing immune function. Psychological effects would ride on top of that effect, with unknown interaction.

Characteristics apparently associated with extended survival in humans are subject to much question. First, the theory is not very strong, nor well supported experimentally. Second, and most important, many of these studies are basically faulty in experimental design.

A good example is the often-quoted one of Blumberg, West and Ellis (1954). In that experiment the patients were judged to be long and short survivors by physicians. However, we know that, first, such judgments are notoriously variable and subject to unreliability. Secondly, with the mix of tumor types involved, many of the patients could not have belonged to the short survivors legitimately since the proportion surviving for five years was about half, at the time of this work. Blumberg completed his dissertation in about two years or so, and estimates of long and short survival were not made, so far as one can tell, prior to his entry into the picture. Therefore the estimates by the doctors could not have been based on actual survival, and there was no validation of the estimates except in cases of advanced-stage cancer such as lung, pancreas, liver, esophagus, all of which have short life expectations after diagnosis. For those he could have gotten actual survival times. There is no indication that he did. From what we can tell, the times were all estimated survival times. Also, there was probable bias in the fact that the doctors must have known when the diagnosis was made. It is well known that those who have already survived a long time will tend to survive beyond that time a greater duration than those whose survival up to the time in question was a short interval. For all these reasons one must be rather uncomfortable with that study of survival and its prediction by MMPI results.

I did an analysis of 12 studies involving prediction, both survival (or estimated survival) and incidence of cancer (Fox, 1982). Among all those studies, every one of the MMPI scales were represented at least once, and no scale was represented more than three times among the 12 studies. Only one showed consistent results in as many as three studies--a high score on the depression scale. The distribution of MMPI-scale frequencies among the 12

studies was not significantly different from chance. The point being made is that the studies estimating survival are not to be accepted at face value. They whould be carefully examined for bias.

It may be of theoretical value to do some speculating. What follows is based on findings in the literature, but is not yet supported by hard data. It is exploratory hypothesizing.

Hopelessness might in some way be analogous to the kind of behavior shown by animals transferred to other cages, which become the most submissive members of the new animal group, where before they were not at the bottom of the pecking order. The finding of a fighting spirit as being associated with longer survival among breast cancer patients (Greer et al., 1979) is not inconsistent with the findings of Sklar and Anisman (1980) that mice that fought persistently when placed in a new social environment did not suffer increased tumor load. It seems to me that the fighters did not necessarily survive longer; it was probable that the others, with hopeless outlook, suffered exaggerated immune suppression because of the corticosteroid output associated with that kind of attitude. Parents of cancerous children, tested for psychiatric status, were found to have elevated corticosteroids when they had poor psychic defenses, but not so elevated levels when their defenses, e.g., denial were strong (Wolff et al., 1964).

The phenomenon of spontaneous regression may be explained in the same way. If a tumor regresses without treatment, as was found by Ikemi (1970) in several cases, one can hypothesize that in his case, not only wasn't the immune system depressed because of increased corticosteroid, it was probably enhanced by the access of a calmness and equanimity toward the world greater than the patient had experienced before. Therefore, one could propose that the corticosteroid level actually fell, thus providing a kind of permanent "window" in the sense of Solomon et al. (1981) and Riley (1981), who also reported a kind of rebound phenomenon after stress had depressed immune function and the stress was removed. But we cannot attribute spontaneous regression found by others to such a phenomenon. This kind of hypothesizing must be explored in studies, and in fact, more than one study attempting to verify the "fighting spirit" hypothesis is going on.

If the hypothesis regarding high corticosteroid and poor immune function associated with depression and lost hope is true, it would explain, in part, why there are so few spontaneous regressions. It must not be forgotten that cancer is a disease that in most cases provides positive feedback, in the sense that as the tumor grows it produces reduced immune function itself, independent of the corticosteroid level (as seen in animals). One must ask, however, whether the lethargy, cachexia and weakness associated with a tumor produce a kind of giving-up syndrome in the animal similar to that

in man, with associated increase in corticosteroid level. In that case it may not be a biological effect of the cancer that depresses immune function, but, perhaps, a greater effect should be attributed to the corticosteroid than we do now. This possibility is researchable.

In regard to the issue of psychic manipulation changing attitudes, and thereby increasing immune function, that may be possible, but there is probably a biological limitation to such a process, which may be added to the reasons given above for the small number of spontaneous regressions. It is the well known ceiling effect. When a biological function is carried out at a point near its maximum, as when cancer limits immune function, very little increase is possible. Thus, if such was the case in any given cancer patient, little could be accomplished because that ceiling could normally not be exceeded. This concept is complicated, however, and evidence shows many cases in which immune function can in fact be increased, as in immune therapy treatment. Yet it may be a limiting factor in many cases.

In summary, if PF are considered to have any affect at all, there is more theoretical reason to expect them to affect prognosis of cancer than its occurrence, but the evidence is far too meager to draw any conclusions. The number of acceptable studies in this field in humans is very small, and the field cries out for good work. But merely carrying out therapy or measuring attitude, together with a look at relapse or survival time--that kind of study will yield only partial answers. We should also have measures of immune function and hormonal levels to make any kind of progress in the theory of this field. Finally, if PF have any effect on survival at all, a big "if", their distribution would probably lead to more cases of short survival than long, but there would probably exist, among those PF, ones associated with (not necessarily ones that cause) improved IS. However, if they did cause improvement they would probably be idiosyncratic and difficult to impose deliberately, if they did not come naturally.

Children

With regard to children, let us look at the two problems, incidence and prognosis. For us to believe that PF affect incidence of cancer we would need to do studies similar to those needed for adults--prospective studies. I know of only one (Duszynski et al., 1981), and that was done on adults by checking stressful events in the records for childhood traumata. Of the four items looked at, parental death, parental divorce, sibling death, and having been the youngest child for less than two years, none showed any excess of cancer incidence at any time in the adults' history. We cannot trust the retrospective studies any more than we could those done

on adults. The issue is open. But we can make some statements. Somewhere around 5-10% of children's cancers are genetic in origin, and it would be hard to attribute any of them to PF. For certain cancers we know they are even more strongly genetic. For example, retinoblastoma is 40% genetic; Wilms' tumor is 40% genetic; and neurofibromatosis, leading to cancer (including both childhood and adult cases) in 30% of those having the disease, is 100% genetic (Miller, 1982).

But besides the findings of Duszynski et al. (1981), there are other reasons for not attributing much, if any, effect to PF. Most spontaneous tumors in man arise from a long-term, repeated assault on tissue, with gradual transformation to dysplasia, which becomes more and more severe, finally to become malignant. Tumors arising from sudden transformation, as from a cosmic ray or X-ray, are less frequent, although they exist. If tumors in children are created in the same way they are in adults, then the creation of malignant tissue is bound to be much rarer, and the capability of the IS to eliminate cancerous cells is less a part of the issue than it is in adults by the very scantiness of malignant cells. (The IS is felt to be the mechanism by which PF affect susceptibility to and progress of cancer.)

Can one assume that any one of the PF proposed for adults in the personality sphere is valid for children? Perhaps each person should judge for him or herself whether the PF named above could apply: inhibited sexuality? denial and repression? self-sacrificing and self-blaming? predisposition to depression? rigid and conventional? excessive expression of aggression? body image constriction? stressful events? Among the stressors, would we find extremes among those who develop cancers? What if it is found, as is distinctly possible from recent studies, that leukemia is viral in origin? Can we call on a defective or poorly functioning IS to say that that is why the child could not fight off a viral DNA transformation? None of these ideas is any more than speculation, because the studies we have done on children in this area can be counted on the fingers, and I know of only one prospective one. We can say virtually nothing about the topic, except that PF effects are probably much less likely in children than adults.

As for the second problem, recovery from an existing tumor, or extending lifespan through effects of PF, we are in the same boat. There is far less evidence in children on the matter than in adults. The recent increased number of cures for children's cancer is clearly associated with improvements in drug therapy and general knowledge of specific disease processes. While it is entirely appropriate to try to make the child feel better by using various behavioral and attitude-adjusting techniques such as imaging (having the child imagine in his mind a fight between cancer cells

and immune system cells), they should never be used with the slightest implication that the child, by using a technique like imaging, can control the disease process. Imagine the terrible burden of guilt that would appear with a relapse.

In adults, I believe that Simonton's claims of extending survival of cancer patients beyond their expected survival by their procedures, which include imaging, are based on fundamentally flawed research, as they themselves acknowledge (1981, p. 683). Under no conditions, therefore, can their results be held to support imaging scientifically for the purpose of extending survival. Far more is this true for its use in children for that purpose, where no studies at all, to my knowledge, have been done on imaging. Moreover, the Simontons themselves caution about generalizing their results (1981, p. 683).

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PSYCHOGENESIS, STRESS, IMMUNITY AND CANCER ETIOLOGY AND PROGNOSIS: DISCUSSION OF DR. FOX'S PAPER

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Although the etiology of most childhood cancers remains elusive, pediatric oncologists find themselves in the paradoxical situation of having effective therapy at hand for about 50% of all malignancies that afflict children. Thus, we are curing leukemia and osteogenic sarcoma before we have a clue as to the cause. That statement isn't entirely accurate because we are now aware of a number of associated genetic conditions, immune deficiency states (Kersey et al., 1973), chromosomal abnormalities, congenital malformations (Bolande, 1977), and environmental events that may predispose a child to cancer or significantly increase the risk of developing a malignancy. Foremost on the list of predisposing causes are such diverse disorders as (1) aniridia-Wilms' tumor syndrome; (2) chromosomal instability syndromes (Fanconi's anemia, Bloom's syndrome, ataxia-telangiectasia) and leukemia; (3) 21-trisomy and leukemia; (4) immune deficiency diseases (severe combined immune deficiency disease (SCID), Wiskott-Aldrich syndrome, ataxia-telangiectasia and lymphoma; and (5) multimodality therapy (alkylating agents and radiation therapy) in Hodgkin's disease or non-Hodgkin's lymphoma followed by a second malignant neoplasm, acute non-lymphocytic leukemia.

In each of these conditions, a normal cell or clone of cells is affected or modified by some genetic state, environmental carcinogen, or other promoter to become a mutant cell (Knudson and Strong, 1972). Following this "first hit," the mutant cell, under the influence of a "second hit" from genetic, physiologic, or environmental factors, is transformed into a cancer cell. Promotion of tumor cell growth can be influenced further by nutrition, hormones, other inborn errors or idiosyncracies of metabolism, and the host's immune response. These complex interactions of spon-

taneous mutations, physiological and genetic modulation, and environmental agents are subject to analysis, control, and investigation.

Unfortunately, Dr. Fox's task in assigning a role of psychogenic causes of cancer is more resistant to testing but some notable attempts have been made particularly in the animal models. As he so carefully emphasizes, mice are not men and mouse behavior is even more difficult to analyze. His task is further compounded by the fact that it is particularly difficult and virtually impossible to relate such diverse features as (1) existence of cancer; (2) risk of cancer; and (3) progress or prognosis of cancer to psychosocial factors. Childhood cancers are diverse and have varying etiologies, but, as Dr. Fox has indicated, the number of cases of cancer attributable to psychosocial factors is vanishingly small, if indeed there is any hard evidence for their contribution. The number attributed to genetic causes is large. The hypothesis that bears testing has been related to immunoregulation and immunomodulation and has been developed as follows:

1) Immune deficiency diseases and states are associated with a higher risk of cancer.

2) Immune deficiency disorders have a genetic basis (e.g. SCID, X-linked lymphoproliferative disease, Bruton's agammaglobulinemia).

3) The immune response can be modulated by psychogenic factors. The data here are primarily from rodents. Short-term exposure of AKR or C57/B6 mice to a daily auditory stressor depressed the lymphocytemediated cytotoxic response while enhancement occurred with longer exposure to sound stress (Monjan and Collector, 1977). In other fascinating experiments, female C3H/He mice carrying the Bittner oncogenic virus and predisposed to mammary tumors, and exposed to chronic environmental stress (not too dissimilar to living in New York City) had a significantly higher incidence of mammary tumors and a significantly shorter median latent period than animals exposed to low stress (equivalent to Montauk living).

4) Stress, depression, and other psychosocial factors may, through neuroendocrine mechanisms, modulate the immune response compromising immunological competence or other effective antitumor surveillance mechanisms and permit a virally-transformed clone from being destroyed during a vulnerable stage, giving rise to inevitable, irreversible, and lethal tumor growth (Riley, 1975). Testing this hypothesis in childhood tumors remains to be done, particularly since there is little if any evidence for genetically con-

> trolled psychogenic factors and only scanty, but certainly inconclusive, evidence that stress, other psychogenic factors, and life events are associated with the occurrence (not prognosis) of cancer in children (Greene and Miller, 1958).

One study not discussed by Dr. Fox is of interest. Jacobs and Charles (1980) used the Holmes-Rahe Life Schedule of Recent Events and personal interviews to study families of 25 children with cancer (mostly leukemia and lymphoma) and a control group of 25 children seen in a general pediatric outpatient department. The demographic characteristics of the two groups were similar. However, the familiar incidence of cancer was significantly higher in the patient group (60% versus 32%). Other statistically significant characteristics in the patient population included a lower incidence of planned pregnancy (32% versus 90%), more somatic and/or emotional problems during pregnancy (56% versus 28%), difficult birth (20% versus 4%) and frequent ear, eye, and urinary tract infections (24% versus 8%). Of most importance, the authors confirmed the earlier controversial findings of Greene and Miller (1958) and found that the patient group experienced a significantly greater number of designated life change events and events of greater emotional significance than did the comparison group. "Events" included changes in residence or school, death of a parent, separations, illness, loss or change for parents and other family members. Unfortunately, multivariate analysis, evaluation of immune function and immunoregulation, cytogenetics and other important biological studies were not performed. It is not surprising that more life events would occur in the families of the study population if there were more deaths or intercurrent illnesses related to familial cancer. Because of the important role of genetics, a better designed study would have corrected for the contribution of this factor in the control group and then analyzed the role of life events.

Spontaneous regression of certain cancers has been attributed to enhancement of the body's immune response by "access of a calmness and equanimity toward the world greater than the patient had experienced before." Neuroblastoma in infancy is a primary example of a tumor that is capable of spontaneous regression. I strongly doubt that the six-month old who was born with the tumor has a Zen experience and new emotional insight resulting in an enhanced immune response.

Speculation abounds in this difficult field of research. Preposterous theories only compound the problems. As Dr. Fox concluded, the field cries out for study but not studies to which we answer "for crying out loud.!"

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COMPLEXITY OF CANCER ETIOLOGIES: PANEL DISCUSSION

Dr. Audrey K. Brown - Discussion Chairperson

I want to tell you of the image I had when Dr. Miller spoke of the mice. I can't imagine the mouse in the maze with gridlock. The stresses will never be quite comparable to New York City!

Do we have a debate going? As I understand it, Dr. Fox's conclusion and Dr. Miller's conclusion are diametrically opposed. Dr. Fox commented that there is more likelihood that there would be an impact of psychosocial factors on prognosis than on etiology. Dr. Miller has categorically stated he doesn't really see that point of view. I don't know if you want to battle it out now or whether I have misinterpreted your findings.

Dr. Fox

I don't think there is that much difference between our positions. I speculate that if psychosocial factors are operative, then on a theoretical basis one would expect that they would be more strongly operative in determining the prognosis. In view of the positive results in animals that Dr. Miller cited, it would be a bit hazardous to conclude unequivocally that psychosocial factors are not operative in the human. We do know that stresses, possibly not identical, but at least in the same ball park as the kind of stresses which animals are subjected to, lead to both increased and decreased immune function in humans and animals. From that point of view, I would be very reluctant to throw that possibility out completely. Because of the animal data, I retain an open mind despite the lack of human data. That is the only real difference between Dr. Miller's and my position. However I feel that there is very little likelihood that psychosocial stress influences prognosis in a substantial way. We might talk about a percent or two of the total variance, but that's trivial. The variance accounted for by psychosocial factors is probably much smaller than the error associated with the determinations themselves.

Dr. van Eys

I have a question for Dr. Fox. In the U.S.A. there are population groups like the Seventh Day Adventists and the Mormons who have a significantly lower cancer incidence. It is attributed to their lifestyle, their diet, and their mind set. Do you have any data and/or reflections on that?

Dr. Fox

Yes, as a matter of fact, a study was done on the Seventh Day Adventists by Phillips, who teaches at Loma Linda Medical School, a part of the Seventh Day Adventists University. Phillips and Kuzma made the suggestion about low stress in their lifestyle. I feel that it's a ball tossed in the air, and so does Phillips. There are no data on this. My judgement about the Seventh Day Adventists is that the bulk of the advantage in their cancer mortality comes from life-style factors related to known epidemiologic factors. The Seventh Day Adventists eat much less meat, and most of them don't smoke or drink. Part of their life style comes from the religion. There is moderation in their living. They are also not subject to many of the sources of pollution and carcinogens that we have, because they don't like additives in their food. I would be very reluctant to take a strong or even a weak position that psychosocial factors have something to do with their lower cancer incidence.

Dr. Alan Hurst - Audience Member - Psychiatrist

I am in the medical psychiatric liaison service at Downstate Medical Center. I don't think there are many people who would argue with the position that environmental factors are responsible at least to some degree in patients with certain types of cancer. Why is it that where everyone is faced with the same type of environmental factors, some people develop the cancer and others do not? My own feelings are that stress has a great deal of importance in producing this disposition. In 1977, Lancet published a study that was done in Australia of a group of bereaved spouses, and compared them with a control group. They were not looking at cancer specifically, but they did find that the morbidity and mortality in the bereaved group was much higher. They thought this involved the immune system, and described decreased lymphocytes. Apparently, the workup was thought to be fairly good, although very difficult to do. I think stress as a cause for cancer is probably very, very difficult to show in a study. There is at least that one good study with humans, not with rats or other animals, that has been done. I believe that it has some significance.

Dr. Fox

Dr. Hurst, do you remember that study?

Dr. Hurst

I have it right here. After your lecture, I went back to my office to search for it. It's Lancet, April 16, 1977.

Dr. Fox

Okay. Yes, I can address both of your points. The first one was: If everybody is exposed to a given carcinogenic environment, why do only some people get cancer and others don't? I want to refer you to a very fine paper that was written by Dan Miller (1980), of the Strang Institute in Manhattan. In 1980, he wrote a paper in which he examined some of the basic causes of cancer. One of the major points he made was that a very large percentage of cancers in people occurred by chance. Now if you take a look at the two hit theory, which is at least partially accepted by most people, you will notice that in order for cancer to occur, both hits have to occur. And the question is: What makes them occur? It turns out that, by and large, the occurrence of such double hits has to be a chance phenomenon.

Now the second thing that is involved is a successful immune reaction. If it happens that a transformation or mutation occurs when an environmental carcinogen affects the body cell, and it produces a kind of cancer cell which can be immediately reacted to by the immune system because there is clear recognition by the immune system of the cancer cell as a foreign agent, then the immune system can attack the cancer cell very nicely. But what if the transformation is of such a nature that there are no strong antigens on the surface of the new cancer cell? In that case, the normal agent that fights such a cell will not recognize it and the cell can grow.

It's possible for some of the immune system cells not to need very many recognition signs--for example, natural killer cells. Cells that do not show very much antigenicity are the ones that survive and grow. However, that requires a very special kind of transformation, and, by and large, the theory is that those particular ones are a matter of chance. If you get a large number of other kinds of transformation, they are taken care of very quickly by several mechanisms, including the immune system, by a number of enzymes in the body that act to repair damaged DNA. That damage repair is the major method by which the body takes care of environmental carcinogens of various kinds. What happens is that in the majority of people, most of the functions associated with that protective set of devices are working. Occasionally, you get a

a kind of transformation such that none of them works very well, I'll give you an example. Let's say you have a DNS damaged cell, and it turns out that the damage to the DNA occurs just before mitosis of the cell. During that time, the DNA repair mechanism cannot work. That means you have the persistence of a transformation into that cell in the daughter cells. Well, this is a rare event. It's a chance event. So it is this kind of chancy phenomenon that leads to the fact that most people are able to handle the cancer cell and only the occasional one succumbs.

It turns out that locally, Stein, at Mt. Sinai in Manhattan, has done some work in which he also found differences similar to those of Bartrop in men who had wives with terminal breast cancer. Schleifer, Stein and others (1980) examined the immune response of the husbands before and after the wives had died. They found changes similar to those that had occurred in Bartrop's study. To that degree, there is support. But, by and large, no one else has replicated the same kind of study.

There are a number of other studies in which it has been shown that certain stress phenomena are related to immune system changes. In one of my papers, I have listed a half dozen or more such studies. However, these studies pick up one element in the triad of connections that must be found. What has been shown is that stress may affect the immune system. The connection from the immune system to the cancer has not been made in the human. This is not to say that the immune system in cancer is not connected in the human, but that those particular changes that were observed in the immune system were not correlated with a cancer occurring in the same people. It must be kept in mind that there are a large number of immune processes. What you have cited is interesting, and should be put aside, in a refrigerator, to hold until we can get several other ingredients to the recipe. Then, we can put them all together and, maybe, we will come out with a cake.

Dr. Miller

I have trouble with that hypothesis as it relates to the pediatric population, because we have genetic immune deficiencies already. We don't have to imply stress as inducing an immune deficiency in the pediatric population that has a significantly increased susceptibility or predisposition to develop leukemia and lymphoma. We know that there are a number of chromosomal instability syndromes associated with either immune deficiency or bone marrow abnormalities, again associated with an increased risk of developing leukemia and lymphoma. I don't believe that the pediatric group has different kinds of malignancies than are found in the adult population. We seldom see carcinoma in the pediatric population, which makes up about eighty-five percent of cancer in adults. We see primarily sarcomas and leukemias. I know no evidence that

implies that immune deficiency in the pediatric population is a stress induced phenomenon. I will grant that there are more neuro-endocrine and psychoendocrine effects that can affect immune responses. But I don't think one has to jump to stress factors when one is looking at genetic causes of immune deficiency in association with pediatric malignancies.

Dr. Fox

May I make a suggestion at this point? The chormosomal deficiencies do not occur in a hundred percent of the leukemias and sarcomas. This means that there is a certain proportion in which that position may not hold. Now it is for those that one might want to address the question: How much does stress enter into the picture? The chromosomal deficiencies Dr. Miller referred to reduce the possible total number of patients that might be affected by stress, but that does not mean that stress has any greater probability of affecting them than any other stress-related disease. So what we have, in effect, is support for the view that I had proposed earlier, namely that for children, the probability that psychosocial factors will cause an increased incidence of cancer is even smaller than in adults.

I would like to continue my answer to Dr. Hurst. The Jacobs and Ostfeld (1977) article that appeared in Psychosomatic Medicine a couple of years ago is critically important to this question. This article is a thorough review of almost all of the bereavement studies. For most diseases other than cancer, there is in fact, an increased mortality following bereavement. In cancer, some studies showed in increase, while others did not. But in those studies that showed an increase, a very peculiar finding turned up that was critically important. In most studies, the excess mortality that followed bereavement occurred within the first half year after bereavement or within the first year after bereavement.

Now, one has to be familiar with a little bit of the biology of cancer to appreciate the implication of this finding. The latent or developmental period for most cancers, except for a very few, is on the order of years, not months. Survival after a diagnosis of cancer runs generally in the region of two to three years these days, which means that almost 90% of the people who had died within a year after the bereavement couldn't possibly have just gotten their cancer during that year. It had to be growing a number of years beforehand. Just because the person died of the disease within that year doesn't mean that the bereavement caused it. Bereavement has, to date, not been demonstrated to cause cancer. Whether bereavement contributes to an increased incidence of cancer over the next five to ten or fifteen years is something else. We are not quite sure of that.

Dr. Flomenhaft

What about individuals with cancer who go into remission as a function of their reaction to certain family events, such as resolving a problematic marriage by a subsequent change in marital status?

Dr. Fox

You are referring to individuals, for example with breast cancers, who have a current median survival time on the order of five-and-a-half years and who during their third year are still in remission. No one has looked at that question. It's a very fascinating one, and I am glad you brought it up. I will make a note of it and see if we can take a took at it.

I would like to respond to Dr. Miller's and Dr. Christ's questions about: How do you separate out the influences of environmental and stress or personality causes of cancer, since the two seem so very much intertwined? Well, there are several ways of disentangling the two influences. One of these is that you make a list of the relevant variables that you know about, test them independently, and if they are not significant, you can just throw them out. You demand a lenient level of significance so as not to make a type II error. (Type II error occurs when a truly relevant factor is rejected as having no influence.) This error increases as the significance level above which the null hypothesis is accepted becomes more smaller, as from .2 to .1 to .05 to .01, etc. Those variables that turn out to be significant are then put into a multivariate analysis.

Let me give a practical example. I was involved in a study of melanoma relapse in which that very technique was used. We had about ten physiological indices of survival other than the psychological ones. Only one of the 11 indices was significant. We retained that 11th one, which, by the way, was the number of nodes found, and put that into a two variable discriminant function analysis. We separated the independent influence of the number of nodes and the psychological variable, and determined a particular weight for each one. This is a very straightforward technique.

A second way of doing it is to match your control and experimental group on the very variable which might be considered to bollix things up a bit. Essentially, by doing that you have removed it. You just have to be careful if you have several variables that are of interest! If that is so and both are also related to the matched variable, you may do what is known as overmatching, and remove some ability to identify a contribution from the other variables. This difficulty has to be avoided, but it is a decent technique.

The third way, which is by far the most frequent, and maybe the most efficient, is a straight multivariate analysis. You put in a number of variables, and at the end of the analysis, you know just how much is contributed by each variable.

Finally, let me remark on Dr. Miller's reference to Greene's (1966) studies of children with cancer. There are deep problems with Greene's study. First of all, it is retrospective and, therefore, subject to all the problems of retrospection. Secondly, Greene's interviews were not blind because the interviewers knew which subjects had cancer. This can be an extremely biasing situation.

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CLINICAL CANCER RESEARCH: PATIENT, PARENT AND PHYSICIAN INTERACTIONS

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INTRODUCTION

The impressive progress and improved prognosis in childhood cancer obtained during the past decade are related to more precise diagnostic tools, more effective multimodality therapy and improved supportive care. Whereas fewer than 5 or 10 percent of children with acute lymphoblastic leukemia (ALL) were long-term survivors in 1965, nearly 60% of children with ALL diagnosed between 1972 and 1975 and treated with a "modern" protocol are alive and free of disease in 1982. A similar record of success is being achieved in the treatment of other hematopoietic malignancies and solid tumors in the pediatric age group. Of the estimated 7000 children diagnosed with cancer in the United States in 1981, at least 3500 will survive their disease and its treatment. In fact, Anna Meadows (1980) at the Children's Hospital of Philadelphia has estimated that by 1990, one of every 1000 adults will be a survivor of childhood cancer.

With a shift in therapeutic strategy from palliation to temporary remission and disease control to an aggressive curative

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intent, the relatively small fraternity of pediatric hematologists-oncologists (more effectively than their colleagues in medical oncology), recognized over 25 years ago the need to unite good clinical care with clinical research. The union was not only compatible with, but responsible for most major and significant advances in the field. These were achieved through either controlled randomized or nonrandomized cooperative group or single institution clinical trials. Clinical research has had a profound and beneficial effect upon the major parameter of success or failure in cancer therapy--disease-free survival. It is estimated that over 70% of newly diagnosed children with cancer are entered on a clinical research protocol, be it the National Wilms' Tumor Study, the Intergroup Ewings' Sarcoma Study, Children's Cancer Study Group (CCSG) protocol 161 for ALL or the Sidney Farber Cancer Institute MADOC protocol for stage IV neuroblastoma. As will be developed in this presentation, pediatric patients have the best chance of surviving if they are referred to a major pediatric cancer center or are entered on a national clinical research protocol study. Participation in clinical research protocol has placed additional burdens and stresses upon patients, parents, siblings and physicians, but from available data, the benefits in terms of improved survival, communication and understanding of disease outweigh the risks.

With improved survival statistics, psychosocial services and research in childhood cancer are undergoing major shifts and changes as well. In the fifties and sixties, when childhood cancer was virtually always fatal, anticipatory grieving and preparation for the inevitable death of the child were de rigeur. The neat compartmentalization of the psychological reactions from diagnosis to death, so in vogue in the psychosocial and pediatric literature 15 years ago, is giving way to a refreshing approach which acknowledges that leukemia and other childhood cancers are not universally fatal but potentially curable. Current psychosocial strategy, so clearly articulated by Koocher and O'Malley (1981) in their recent text The Damocles Syndrome, is preparation for life, not death. However, in patients who have sustained relapses and in whom an initial favorable prognosis is automatically converted to an extremely unfavorable one, the previously held concepts of emotional and psychological coping experiences of parents and siblings of fatally ill children are still valid and form a useful framework for caregivers offering intervention and support. Complicating the transition from diagnosis, initial successful remission, relapse, and death are the contributions and mixed blessings of biomedical technological advances including the availability of intensive care units, the introduction of potentially beneficial experimental therapeutic agents, and bone marrow transplantation. An emerging paradox is the prolongation of life, albeit for a few weeks or months, in a child with little or no chance of long-term survival. On the other hand, bone marrow transplant can offer cure when con-

ventional therapies have been exhausted and have nothing further to offer. This new technology and clinical research at the frontier of medical science are adding new dimensions to the well-recognized psychosocial issues of standard therapy. We know very little about the emotional/psychological effects of experimental chemotherapy (Phase I/II drugs) and bone marrow transplantation upon the patient, family and physician. These are uncharted waters for the psychosocial researcher and much of my presentation in this area will relate to personal experience rather than published studies.

The major purpose of this paper is to review the recent progress in the treatment of childhood cancer utilizing standard and experimental therapies, and the impact of clinical research trials on the patients, the family and the physician.

CLINICAL CANCER RESEARCH-AN OVERVIEW OF CURRENT RESULTS

The incidence of childhood cancer has not changed significantly since 1960, but dramatic improvement in disease-free and overall survival have occurred in acute leukemia, lymphoma, Wilms' tumor, bone and soft tissue sarcoma (Siegel, 1980; Hammond, Bleyer, Hartmann Hays, and Jenkin, 1978; Van Eys and Sullivan, 1980). As noted in Figures 1 and 2, in 1964-66 the median survival in acute lymphoblastic leukemia was about 18 months and only 10-15% of children were long-term survivors five or more years after diagnosis. In contrast, over 60% of children entered on CCSG protocols 101 (1972-1975) and 141 (1975-1977) are surviving five or more years and the statistical cornerstone of the effectiveness of a clinical trial, median remission duration or median survival has lost its value and significance. The step-wise improvement in overall results occurred because of (1) refinements in laboratory diagnosis, (2) introduction of multiagent chemotherapy programs to induce remission, now routine in about 95% of all children, (3) intensive care with blood component therapy, antibiotics, nutrition and metabolic support during the initial period of myelosuppression, (4) prophylactic therapy of the central nervous system with intrathecal methotrexate and cranial radiation, and (5) more effective drug combinations utilized to suppress leukemic cell proliferation and to prevent recurrence of disease.

Similarly, in childhood solid tumors (Sutow, 1981), multimodality therapy using advanced oncologic surgical, radiotherapeutic, and chemotherapeutic techniques, disease-free survival has increased from less than 20% in the 1950s to 60-80% in the 1970s for most common childhood solid tumors. Brain tumors and metastatic neuroblastoma have resisted this impressive record of improved survival. Biochemical, immunologic, and nuclear imaging have improved our diagnostic acumen in solid tumors and have contributed immeasurably to these results.

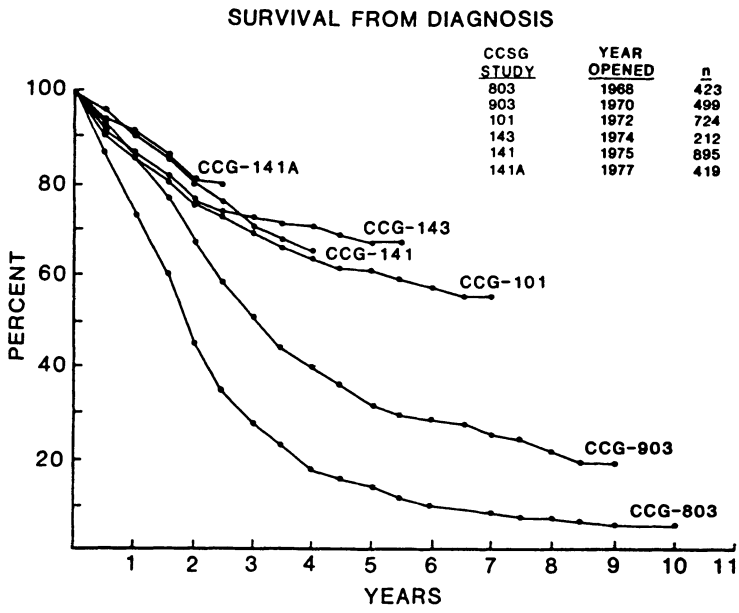

Fig. 1. Improved survival in childhood acute lymphoblastic leukemia 1968-1977 through cooperative group trials. (Siegel, 1981)

Clinical research has been a major factor in the improved prognosis in childhood cancer. Virtually every major and significant advance in cancer therapy has been achieved through either controlled, randomized cooperative group or nonrandomized single institution clinical trials designed to improve upon earlier results by (1) testing new treatment regimens or schedules, (2) increasing or decreasing the intensity, morbidity, or duration of therapy, (3) refining the classification and staging of diseases, (4) tailoring therapy to subsets of patients with differing prognosis, and (5) applying biologic principles to therapeutic strategies. It is unlikely that any single institution today can mount and complete a controlled clinical trial testing treatment regimen A versus treatment regimen B in disease X within the restraints imposed by time, patient-numbers, budget, and ethics. And as the therapeutic results in children continue to improve, even larger numbers of patients requiring prolonged periods of patient-entry will be required to answer the posed clinical question, the relevance of which may be lost if the proposed clinical trial

requires five years for patient entry and five more years of follow-up. Small pilot studies at a single institution can break new ground and suggest new approaches but most require confirmation in a larger controlled trial in which the new "experimental" regimen can be compared to standard "best available" therapy.

The evolution of clinical research protocols has been marked by increased intensity or "aggressiveness" of therapy. The use of multiple agents, associated with synergistic therapeutic and occasionally compounding toxic effects, surgical procedures including "second look" surgery to determine the extent or presence of residual disease, and more liberal use of radiotherapy in combination with or following chemotherapy and surgery have exacted a toll on the larger number of children surviving their cancer. The late effects of combined modality cancer therapy include organ dysfunction (gonadal, endocrine, hepatic, pulmonary, cardiac, genitourinary), permanent physical disfigurement, growth and secondary sexual developmental retardation or delay, neuropsychological dysfunction with learning disability, and most frightening, second malignant neoplasms related to chemotherapy and radiation therapy, induced alteration or deficiency of the immune system, or genetic predisposition (Meadows, Krejmas, and Belasco, 1980). In the era of short survival, late effects of cancer therapy were not the primary concern of the clinical investigator. Few patients lived long enough to develop them. Today, late effects of cancer therapy are a major concern of every clinical researcher designing protocols in the 1980s. With success has come the incentive to maximize effectiveness and minimize acute, immediate, and late toxic effects of cancer therapy. Before we had the luxury of diminishing the intensity of the treatment in selected patients with localized Wilms' tumor or favorable prognosis ALL, successive treatment programs were akin to raising the ante in a poker game. Larger doses of more drugs, more extensive radiotherapy and more aggressive surgery were employed to produce the results achieved in the 70s. However, rather than throw in more chips, we have learned that not all patients with ALL require cranial radiation or five years of maintenance therapy. Radiation therapy is unnecessary in children with Stage I Wilms' tumor and a relatively short 10-week course of adjuvant chemotherapy with actinomycin-D and vincristine results in a 90% or greater survival (D'Angio, Evans, Breslow, Beckwith, Bishop, Feigl, Goodwin, Leape, Sinks, Sutow, Tefft, and Wolff, 1976). The answers to these vital questions came from randomized trials in which patients were assigned by chance to one regimen with or another without radiation therapy. Since each required informed consent and parental permission, parents of children with cancer have been unsung partners in the tremendous advances made in the treatment of their children. I will return to the psychodynamics of this interaction but it is obvious that clinical research has added a new dimension and burden to patients, parents and physicians already overwhelmed by the

diagnosis of cancer.

Psychosocial Issues

With the improved outlook in children with cancer, psychosocial issies have evolved from a concentration on the dying child, and anticipatory grief and bereavement in the parents and siblings to a view of childhood cancer as a chronic life-threatening illness that is potentially curable (Koocher and O'Malley, 1981). The recent psychosocial literature emphasizes the problems of living with cancer rather than on dying. Unfortunately, most of the reported studies were completed in a less optimistic and upbeat period of cancer therapy. Although the available chemotherapeutic agents in 1965 offered an 80% chance of inducing remissions in ALL, few patients survived beyond three years. Accordingly, parental preparation for their child's death and the various stages or compartments of their emotional reaction to the inevitable event were described by a number of investigators in the 60s and early 70s. Natterson and Knudson (1960) defined a triphasic reaction in mothers: at diagnosis an initial disturbed reaction with denial of reality; a more rational interim (maintenance) with energy directed toward realistic measures that offered hope of saving their child's life; and an integrated terminal reaction in which energy was directed away from the child. Chodoff, Friedman, and Hamburg (1964) defined three similar overlapping phases: (1) the shock and unreality at diagnosis with intellectual acceptance and emotional nonacceptance, (2) with recurrent or progressive disease, curtailment of hope and anticipatory grieving and (3) detachment and philosophical resignation to the death of the child. Futterman and Hoffman (1973) described the parental adaptation to death as anticipatory mourning processes comprised of four parts: (1) acknowledgement, (2) reconciliation, (3) grieving, and (4) memorialization and detachment. Knapp and Hansen (1973) adapted their stages of anticipatory grief after Kubler-Ross: denial, anger, bargaining, depression and acceptance. This early literature suggested that adaptive "good copers" and well adjusted parents could progress through these phases of anticipatory grieving and that maladaptive "poor copers" were arrested somewhere in their grief reaction and were left with significant late psychological effects after the death of their child. For most parents today beginning the process of anticipatory mourning at the time of diagnosis is inappropriate and may be counterproductive. The emotional demands placed upon parents are overwhelming and full of paradox if death were inevitable. They may acknowledge the inevitable death of their child yet maintain hope, actively care for their child but delegate the responsibility of care to trained medical and nursing personnel, trust in their physician yet accept the limitations of medicine, emotionally provide for the child yet face the inevitable and become detached (Futterman and Hoffman, 1973). The parents in this setting would be in constant conflict between externally directed behaviors

including participation in the child's care and fulfilling all other personal, social and professional responsibilities and internally directed behaviors including the ability to manage and control emotional reactions (Kupst and Schulman, 1980). Kaplan, Smith, Grobstein, and Fishman (1973) studied adaptive and maladaptive coping responses in 50 families of children with leukemia. "Adaptive copers" comprehended the serious nature of the illness and its fatal course, were able to communicate this to the family and had appropriate feelings of grief. Maladaptive copers, comprising 87% of their study population, denied reality, sought other options and opinions, kept their child unaware of the diagnosis, were unable to grieve appropriately, were hostile to the medical staff, and showed an early abdication of parental responsibilities. In a subsequent study performed after the child's death, Kaplan and coworkers (1976) found adaptive behavior in only 12% of the families. In 80%, emotional problems emerged after the diagnosis and in 20% problems pre-existed the diagnosis but were exacerbated by it. A post mortem survey of 173 family members revealed one or more problems in over 70%. Spinetta (1978) found that only 7/23 families adapted well to life after the death of a child.

One psychologist's view of psychopathology may be another's of adaptive coping behavior. Thus it is not surprising that other investigators found a healthier emotional environment in childhood cancer families. Chodoff et al. (1964) and Futterman and Hoffman (1973) detected appropriate adaptive coping behavior in families of children with leukemia. Stehbens and Lascari (1974) found 37 of 40 parents fully recovered within six months after their child's death and in 1/3, marital relations were felt to be stronger. During the terminal phase of illness, sleep disturbance, loss of appetite and preoccupation with the child were observed. In a selected population of "good copers", Schulman (1976) uncovered a number of common qualities in the parents including a good self-concept, openness, honesty, an optimistic attitude, an affirmation of life rather than a denial of the illness, and an atmosphere of mutual support. The child was treated as an individual separate from his or her illness and the parents learned to "live for the present and make the most of the time they had." From these reactions it would appear that adaptive behavior in an era when the prognosis in childhood cancer was poor, was more effective if optimism, hope and an affirmation of life rather than an acceptance of death were the key emotional reactions. Unbeknownst to these adaptive parents, they had discovered coping behavior suitable to the modern era of improved outlook, despite the fact that psychologic dogma was that death was inevitable and must be accepted.

These studies were flawed by their retrospective nature, limited perspective with regard to a particular phase of disease (at diagnosis, after death), distorted responses based upon recall and biased by the potential to present a more favorable picture.

Kupst and Schulman (1980) evaluated coping behavior in 43 families of children with leukemia and 25 with miningitis, the control group. Age and sex distributions were similar but the socioeconomic scale in the miningitis families was lower. Coping adjustment scores were similar in the leukemia and meningitis groups and scores in mothers and fathers were significantly correlated with one another. In the six families with maladaptive coping behavior there was a history of previous discord, marital problems, emotional disturbance, and disorganization.

Foster, O'Malley and Koocher (1981) recently reported results of extensive interviews in 190 parents of 119 long-term survivors of childhood cancer. They found (1) marriages were stable over time and that the child's cancer did not induce marital discord; (2) parental income and socioeconomic status were inversely correlated with the child's psychosocial adjustment; (3) in order of importance, persistent parental concerns about their surviving child included long-term effects of treatment, recurrence, sterility, general physical condition, ability to obtain insurance, emotional stability, fullness of life, life expectancy, and employment. Nearly 3/4 of the parents became closer as a couple and 92% grew

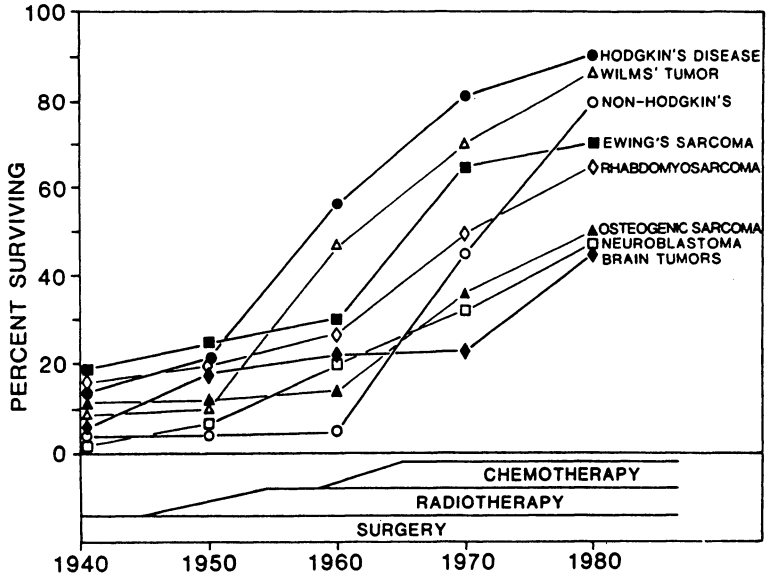

Fig. 2. Improving 2-year disease-free survival of children with solid tumors (1940-1980). (Siegel, 1981)

closer as parents (Table 1). Stressful points during the course of their child's treatment included the initial diagnosis, a shock lasting 3 - 12 months, changes in treatment, disease recurrence, hospitalizations and elective cessation of therapy (Table 2).

Not unexpectedly, hope and communication were the most important coping mechanisms. Others included faith, support of spouse, sense of humor, quality of medical care, maturation of child to adulthood and freedom from decision-making. This is a refreshingly realistic and optimistic strategy for coping when compared to the obsolete, sterile, compartmentalized stages proposed in the sixties.

Table 1

Parents' Concern about the Former Patient at Interview (N=119)

Order of Frequency	Issue	N		
		Mentioned as an Issue	Mentioned as Nonissue	Not Mentioned
1	Long-term effects of treatment	90	9	20
2	Recurrence	85	11	23
3	Ability to produce children	66	26	27
4	General physical condition	56	35	28
5	Ability to obtain health or life insurance	49	34	36
6	Emotional stability	40	42	37
7	Whether life will be less full	38	46	35
8	Life expectancy	36	39	44
9	Whether able to get job and be self-supporting	18	58	43
10	Other	14	9	96

Table 2

Reported Impact of Cancer on Marital Closeness (N=176)

	N Mothers	%	N Fathers	%
	Closeness as Couple			
Grew closer	69	70.4	58	74.3
No change	17	17.3	16	20.5
Grew less close	12	12.2	4	5.1
Total	98	99.9	78	99.9
	Closeness as Parents			
Grew closer	85	86.7	72	92.3
No change	10	10.2	6	7.7
Grew less close	3	3.1	0	0
Total	98	100	78	100

The earlier literature on marital discord and divorce is conflicting, and suggested that marriages were being destroyed by the stress of childhood cancer (Sultz, Schlesinger, Mosher, et al., 1972; Binger et al., 1969). Others (Kaplan et al., 1976; Oakley and Patterson, 1966; Stehbens and Lascari, 1974; Hamovitch, 1964; and Begleiter, Burry, and Harris, 1976) reported a divorce rate of 0 to 17% in families with chronically ill children. In a more recent well-designed and controlled study Lansky, Cairns, Hassanien, Wehr, and Lowman (1978) found a person-year divorce rate of 1.19%, slightly lower than the 2.03% person-year divorce rate in the region. However, marital stress and disharmony as measured by the Arnold sign indicator, was significantly higher in couples of children with cancer than in normal control and hemophilia families but significantly lower than in "normal" couples receiving marriage counseling (Figure 3).

Clinical Trials in Children - Effects on the Family

There is little doubt that clinical trials benefit medical science, the clinical investigator-scientist and cancer patients in general. The progressive stepwise improvement in rates of complete remission, duration of complete remission, and number of long-term survivors achieved through clinical research protocols provides scientific and ethical justification for continuing clinical research programs in pediatric oncology. Thus society, the greater good, and the larger cohort of children treated in a randomized cooperative group protocol are benefitting. Is there any evidence that entry on a clinical research trial is beneficial to the individual patient? Does entry on a clinical research protocol study imply the best available therapy and the best chance for cure? Are there differences in the adaptive behavior of

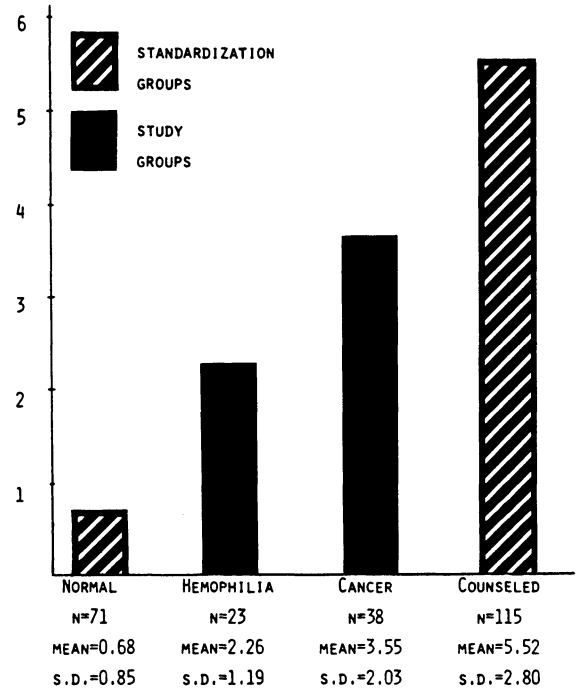

Fig. 3. Mean total Arnold sign indicator score, a measure of marital stress and disharmony, for couples in normal, hemophilia, cancer, and counseled groups. Counseled couples scored significantly higher than hemophilia and normal couples. (Lansky et al., Pediatrics 62:184-188, 1978)

patients and parents whose children are enrolled in a clinical trial at a university or pediatric cancer center compared to those treated with standard therapy at a community hospital? It is estimated that 50-70% of previously untreated children with cancer are entered on clinical trials and research protocols of pediatric cooperative groups (CCSG, Pediatric Oncology Group-POG), or single institution pediatric cancer centers (MSKCC, Sidney Farber Cancer Institute, Roswell Park Memorial Institute, MD Anderson Hospital). Some of the latter participate in collaborative clinical trials of cooperative groups as well as their own institutional programs. An extensive outreach network of affiliate hospitals is now working with parent institutions in the cooperative groups through Cancer Control Programs, further increasing the number of newly-diagnosed children entered in clinical trials. Approximately 30% of children enrolled in CCSG Phase III protocols are being treated in affiliate cancer control hospitals and for the most part are children who would not have been referred to the Cancer Center or parent institution for diagnosis and treatment. Thus the outreach program has upgraded the quality of medical care now provided to children with cancer and enhances the skills of community pediatric oncologists who are now able to participate in a major cooperative group effort.

Sketchy data exist and support the contention that children treated at a pediatric cancer center or on a national treatment protocol have a better survival than nonprotocol patients treated at a nonaffiliated community hospital (Meadows, 1979). A priori, the facilities, resources, and cojoint experience and expertise at a major cancer center are superior to those in a small hospital with a low accrual of pediatric cancer patients. Furthermore, few community hospitals have a full multidisciplinary support team of pediatric oncologists, surgeons, radiotherapists, pathologists, clinical pharmacologists, nurse oncologists, psychiatrists, clinical psychologists, social workers, nutritionists, rehabilitation therapists, immunologists, infectious disease physicians, and other medical-pediatric subspecialists required to provide complex, intensive and comprehensive care. Meadows (1979) reported that although the results of induction therapy in newly diagnosed children with ALL were similar at Children's Hospital of Philadelphia compared to those obtained at unaffiliated community hospitals, survival was significantly longer in protocol patients, and particularly those with a poor prognosis. In a study reported from the Connecticut Tumor Registry, five year survival was significantly better when children with medulloblastoma were treated at the university cancer center than at the community hospital (74% versus 29%). Results were similar in children with brain stem gliomas (40% versus <10% [Duffner, 1981]). The quality of institutional participation in a protocol varies from center to center. Independent institutions using the National Wilms' Tumor Study protocols are reporting the same excellent results as CCSG institutions, supporting the concept that the benefits of clinical research can filter to the

community.

Utilization of a cooperative group protocol does not guarantee superior results. In CCG 251, a protocol for children with ANLL, the complete remission rate, a key predictor of outcome, was significantly higher at full member institutions compared to affiliate and cancer control hospitals (75% versus 50%, $p = 0.025$ [Nesbit, 1981]). Better supportive care facilities and resources and more experienced personnel may account for the difference. Inferior protocol compliance at the community hospital was reported as well in Hodgkin's disease stage I-II by Ternberg and Hays (1981). In a soft tissue sarcoma trial of SIOP (International Society of Pediatric Oncology), and EORTC (European Organization for Research on Treatment of Cancer) larger centers had a better compliance record than small centers with few patient entries (Sylvester, Pinedo, DePauw, Staquet, Buyse, Renard, and Bonadonna, 1981). Complications of treatment are not necessarily higher at the community hospital when the treatment protocol is supervised by the university cancer center (Kisker, 1980).

In the simplest of all worlds, unencumbered by clinical research, a family with a newly diagnosed child with suspected ALL would be referred by a pediatrician to a university pediatric cancer center for diagnosis and treatment. The parents' initial reaction of shock, disbelief, isolation of affect, efforts to disprove the diagnosis, unrealistic planning for the future, inability to mobilize and avoidance or denial of the worst case, death, would be allayed by a compassionate and understanding pediatric oncologist. Prognostic implications would be reviewed based upon current knowledge. Ideally the parents preconceived notions about the disease, its treatment, side effects of therapy, their own guilt and projections of symbolic meanings and anxieties onto the child would be discussed to begin the adaptive and educational process and to open avenues of communication between dyads of mother-father, parent-patient, patient-physician, and parent-physician. The child's acute reaction to the diagnosis is based upon his age, and his intellectual and developmental maturity, but commonly, anxiety, guilt, fear of physical harm, helplessness, total dependency, isolation, rejection, and fear of death are expressed. The omniscient and all powerful physician-healer, equipped with latest medical resources will reassure the family and patient, and gain their trust by outlining an effective and successful treatment program, most likely associated with a complete remission rate of 90-95% and a projected 60% chance of disease-free survival. The newly diagnosed child and family is at the mercy of the pediatric oncologist. Lacking the medical knowledge, wishing to please the physician and acquiesce to his superior knowledge and experience, concerned only about cure, parents would feel more secure in the knowledge that no further questions regarding the treatment of ALL need be asked and that curative therapy would be given to their child. However,

this approach would impede medical progress because, unfortunately, ALL is not curable in all patients and probably won't be for another generation. Thus, at the time of intense stress and vulnerability, parents are now being asked to enroll their child in a research protocol with random assignment to one of a number of possible treatment regimens, more invasive procedures, indefinite duration of therapy again determined randomly and ethical uncertainties about whether or not they are acting in the best interest of their child (Hamilton, 1981). Despite this dilemma, few parents reject the offer to participate in a clinical research protocol. The trust and partnership established between parent and physician imposes additional burdens of responsibility upon both. With full disclosure about the state of the art in the treatment of childhood ALL and the need for continued progress, and an in-depth review of the proposed clinical research protocol with truly informed consent, there has been a 100% enrollment of newly diagnosed children with ALL at MSKCC on a randomized clinical protocol during the past four years. Consent consists of a fair explanation of the procedures to be followed and their purposes, including (1) identification of procedures, such as serial bone marrow aspirations and biopsies to evaluate the completeness of response to induction therapy; (2) a description of attendant discomforts and risks reasonably to be expected; (3) a description of any benefits reasonably to be expected; (4) a disclosure of any appropriate alternative procedures that might be advantageous for the child; (5) an offer to answer any questions concerning procedures and treatment; (6) an instruction that the parents are free to withdraw consent and to discontinue participation in the clinical trial at any time without losing treatment benefits; (7) a guarantee of confidentiality, and (8) a statement advising subjects of the availability or nonavailability of medical treatment or compensation for physical injuries incurred as a result of participation in the clinical trial.

The consent form itself is a source of additional stress and burden to parents. Hardly in a position to take on more guilt, they are asked to relinquish control, trust in the physician, leave choices to chance and accept the uncertainties and potential risks of a new treatment program. This requires total faith and trust, but checks and balances are available and mandatory to protect the child and his parents. Institutional review boards must approve all clinical research protocols and it is unlikely that in pediatric oncologic research unethical studies are being performed. The review process of a national protocol is time-consuming and prolonged and the final product is often a compromise, generally devoid of controversy. In the evolution of serial protocols, relatively minor new changes are made and are based upon the results of the previous trial. Ongoing analysis permits timely closure of a study that has answered therapeutic questions. At that point, all patients in the trial should have access to the preferred treatment.

The pediatric oncologist-investigator is usually highly motivated to find a new means of treating or understanding leukemia and to gain this information as quickly as possible. He also wishes to enhance his professional status and publish his results before any of his peers, generally all competing for an ever-shrinking source of funds. And he is concerned for the welfare of his patients enrolled in the study. The last should be the first, but the actual ranking of importance of these motivations varies from investigator to investigator and from study to study, but regardless of the order, these motivations explain the pressure to enroll patients on study to minimize the risks, maximize the benefits and worthwhile nature of the research and to complete the trial as expeditiously as possible. In fact, his approach is similar to mine in this presentation in which I will attempt to rationalize the importance of clinical research trials.

Let us examine in detail a current randomized clinical research trial for the treatment of childhood ALL and identify areas and times of parental stress superimposed upon those induced by the initial diagnosis itself.

> Joe C is a 3 year old boy referred to MSKCC by his pediatrician with a two week history of pallor and petechiae. On the basis of clinical and laboratory presenting features, a diagnosis of "good prognosis" ALL was made. He was an only child of Italian-American parents. The mother's father had recently died of metastatic colon cancer after a long and painful illness complicated by severe side effects of chemotherapy and radiation therapy, and she had given him total care during the prolonged terminal phase. She balked at therapy and was convinced that leukemia, like carcinoma of the colon was not curable and that the "treatment (chemotherapy) was worse than the disease." She was told by a consulting internist-hematologist that Joey would die in one month if he wasn't treated but that treatment would be more personal at the community hospital than at the Cancer Center where he would be treated "like a guinea pig" in an experiment by doctors who weren't interested in him or his parents. His pediatrician, who trained at a neighboring medical center, recommended his transfer to the Cancer Center. In the presence of the pediatrician, informed consent was obtained to enroll the patient on CCG 161, the current study for good prognosis ALL.

The purpose of CCG 161 is (1) to determine whether CNS leukemia can be prevented without using cranial radiation, (2) to determine whether monthly pulses of vincristine (VCR) and prednisone (PDN) are required in addition to standard daily 6-MP and

weekly methotrexate during maintenance and (3) to determine the optimal duration of therapy 2 versus 3 years. As can be seen from the schema (Figure 4) all patients are induced with vincristine, prednisone, L-asparaginase and intrathecal methotrexate. A complete remission rate of 98% has been achieved to date. On day 28, patients are randomly assigned to one of four CNS prophylaxis/ maintenance regimens with or without cranial radiation and with or without monthly pulses of VCR and PDN. The dose of radiation therapy was reduced to 1800 rads and patients not receiving radiation are treated with IT MTX every 84 days. After two years of complete continuous remission all males are required to undergo open bilateral wedge testicular biopsies. All patients free of disease are then randomly assigned to discontinue or continue therapy for one more year and then discontinue. This study was opened to patient entry in February, 1978. Nearly 300 patients have been entered and the preliminary results indicate that minimal therapy (no radiation, no pulses of VCR and PDN, two years of maintenance) is as effective as the regimens employing maximal "standard"

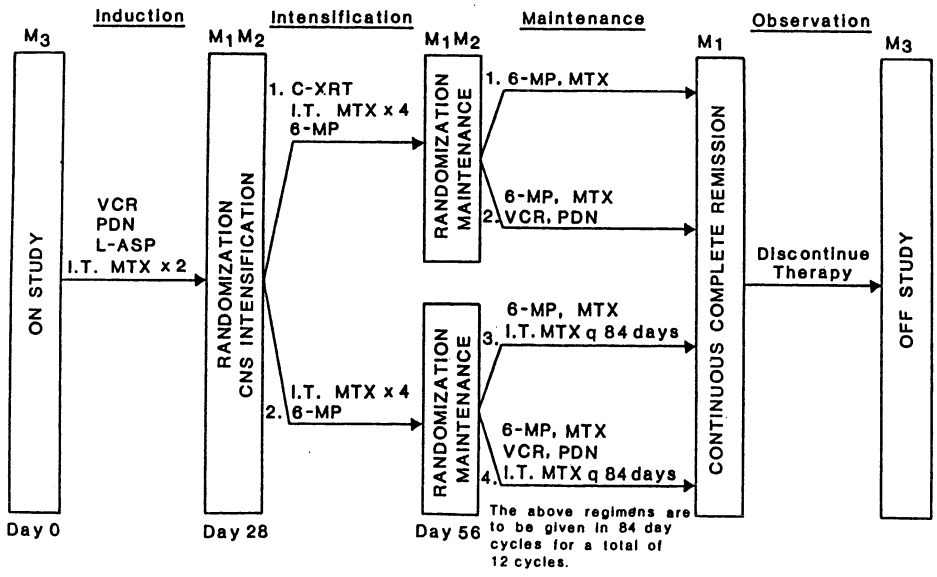

Fig. 4. Schema of CCG 161, a protocol for newly diagnosed children with ALL and good prognosis defined by age and initial WBC.

therapy. In prior studies using similar "standard" therapy, 75% of good risk patients are alive five years or more after diagnosis and in first remission. Although the early results in CCG 161 suggest the same favorable outlook, more encouraging is that the study objectives of minimizing toxicity and maximizing outcome are being met.

When the study design was presented to the parents, this objective was stressed. The parents response was "if this were your child, which regimen would you select?" Others have asked "if you know the end results of the study already, which regimen do you think will become the basis for the next study?" Or, in other words, will the objectives of the study be met, the null hypothesis proven, and the best regimen incorporated into the next generation of studies. Obviously, a goal in clinical cancer research is to use regimens with the highest benefit--risk ratio. The desired goal in CCG 161 would be to demonstrate that the least toxic regimen is as effective as the more aggressive regimens.

The medical researcher accepts the premise that CCG 161 is worthwhile, is theoretically sound, uses appropriate scientific and statistical methodologies and has risks commensurate with the benefits. He or she should have no qualms about subjecting the patient and their vulnerable and distraught parents to the uncertainties of a clinical trial.

Concerning the ethics of clinical trials, Canon Hamilton (1981) of the Washington Cathedral has stated randomization is essential in clinical trials "when there is sufficient uncertainty about the therapeutic value of a new procedure or drug or when doubts arise regarding the efficacy or damage caused by an existing procedure or drug." More succinctly, good science is good ethics; bad science is unethical. The clinical researcher, in obtaining consent from parents to enter a child on a clinical research protocol study, establishes a new relationship of responsibility with the parents and his patient. Through communication, education, full disclosure of risks and benefits, and group meetings, I have learned that parents benefit from the knowledge that their child is part of a larger national effort designed to improve the outlook not only in their child but in other children with the same disease. As Penman (1981) has clearly demonstrated, the initial trust in and dependence of parent or patient on the physician are the key determinants of obtaining informed consent but once obtained, most parents have a much more optimistic, realistic, hopeful and positive involvement in the treatment of their child's illness conforming to the adaptive responses considered to be key by Koocher and O'Malley (1981).

Participation in parent discussion groups, particularly early in the treatment of cancer has been extremely helpful to parents of newly diagnosed patients (Sachs, 1980; Stolberg and Cunningham,

1980). These group meetings, preferably attended by both parents, can be educational-informational or experimental-therapeutic (McCollum, 1975). In the former type, participating oncologists and nurse practitioners can review the rationale, objectives and progress of clinical trials, permit the parents to ask questions freely about the progress in the field, and share with the parents their concerns, reservations, doubts, uncertainties, and fears about their child's progress or lack thereof. Sharing experiences, particularly during the early phases of treatment, with regard to personal, patient, and sibling reactions has been a great source of support and strength for parents. Veterans of the parent group meetings whose child has been in complete continuous remission for years or who may even be off therapy have been particularly important morale-boosters. They and their children have survived the various phases of treatment and developed positive adaptive coping behavior. They provide tangible evidence that children can survive cancer and parents can be supportive during crisis periods (Koocher and O Malley, 1981) including hospitalizations for neutropenia and fever, reemergence of symptoms similar to those at the onset of disease, death of a friend or relative from cancer, time of bimonthly bone marrow and spinal taps to reconfirm state of remission, at the end of chemotherapy, and anniversary dates of diagnosis or isolated relapses. Hypothetical time graphs of stress during the onset phase and later phases of cancer treatment are plotted in Figures 5 and 6 (Koocher and O'Malley, 1981a).

Identification of significant prognostic factors not only have permitted the pediatric oncologist to individualize and tailor therapy for specific subsets of patients but also to provide parents with a more realistic appraisal of outlook. Predictions of survival based upon retrospective analyses of prior study results is dangerous because each child has either a 0% or 100% chance of survival despite an overall survival statistic of 60%. Mulhern, Crisco, and Camitta (1981) evaluated the prognostic views of 25 pediatric patients with leukemia, their parents and their physicians. Complex, subtle patterns of disagreement and misunderstanding were uncovered. Mothers and fathers overestimated the physicians more somber view, physicians underestimated prognostic perceptions of mothers and fathers and the patients were more optimistic than their mothers, fathers, and doctors. Mothers associated a good prognosis with male sex and duration of remission, and fathers selected male sex, early age at diagnosis, common ALL immunologic subtype and duration of remission. The physicians stressed immunologic subtype, initial WBC, sex and age and considered T-cell leukemia the poorest prognostic characteristic although they did not perform either univariate or multivariate analyses of their study population to show that their preselected prognostic factors correlated with prognosis. They suggested that disagreements and misunderstandings concerning prognosis may be responsible for unusual or maladaptive patient and family coping, but this may be iatrogenic if the physicians transmit

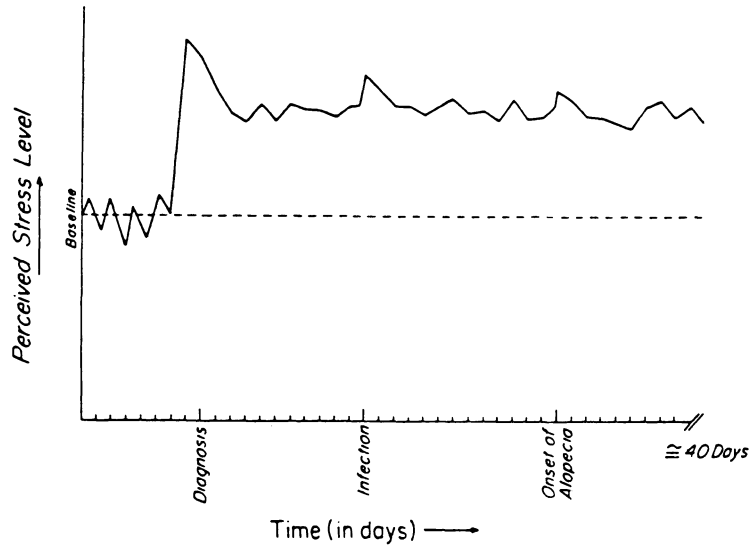

Fig. 5. Hypothetical stress/time graph showing onset and phase of career. (Koocher and O'Malley, 1981a)

misinformation concerning prognostic factors. Large scale studies (Greaves, Janossy, Peto, and Kay, 1981; Riehm, Henze, Jobke, Kornhuber, Langermann, Ludwig, Muller-Weihrich, Ritter, Schellong, and Treuner, 1981) demonstrate that cell surface markers are not an independent prognostic factor stressing the problem of physician-induced maladaptive behavior. On the other hand, overdependence on prognostic factors has led to an overoptimistic estimation of survival in some patients. Parents are devastated at the time of unanticipated relapse in a patient with a supposedly good prognosis and a 90% chance of survival. The initial reaction of optimism is replaced by one of profound disillusionment and disappointment (Nir, 1981) setting into motion a shift from hope and optimism to despair and proparation for death.

The physiologic effects of this psychological trauma have been quantified. Friedman and coworkers (1963) measured corticosteroid excretion in parents anticipating the death of their child and not surprisingly found an association between the stress

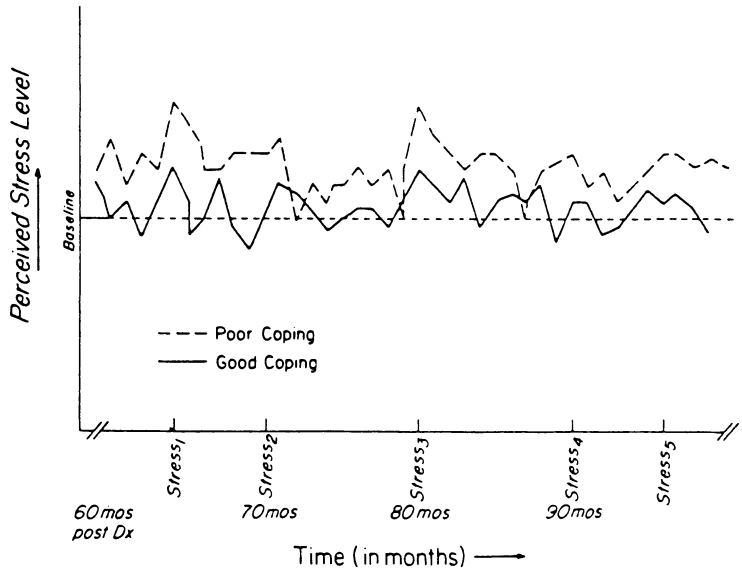

Fig. 6. Hypothetical stress/time graph: good versus poor copers. (Koocher and O'Malley, 1981a)

at diagnosis and first relapse and urinary steroid excretion. It is well recognized today that an adverse event such as bone marrow relapse on therapy carries an extremely poor prognosis. Median survival after bone marrow, testicular, or central nervous system relapse was 10, 14, and 22 months respectively in a recent CCG trial (Miller, 1981), despite intensive retreatment. Is is unlikely that a child sustaining a relapse while on therapy will be a long-term survivor. The clinical implications of relapse are understood clearly by most parents. This adverse event will require a re-structuring of psychosocial support for the family and a shift to anticipatory grieving.

The end of therapy (two or three years after diagnosis) is another period of stress and decision-making. Some investigators (Alby, 1980) have suggested that ending chemotherapy is a crisis period because it implies a breaking-off of a complex dependency between the patient and chemotherapy. Drugs were described as "lost and irreplaceable friends," akin to addiction. Chemotherapy

implied a reassuring link between the patient and the hospital and physician. Cessation implied a rocking of the boat, a severing of a lifeline, and brought to the surface fears of abandonment, anxiety, loss of secondary gain and renewed feelings of guilt, best articulated by a patient who said "to accept healing is to have forgiven and to be sure that your parents have forgiven you all the burden and distress caused by disease."

Our recent experience in randomized trials belie this anecdotal account. Whereas acceptance of randomization is extremely high at the onset of a clinical trial, 40% of parents refuse late randomization designed to determine the optimal duration of therapy (Miller, Leiken, Albo, Saher, and Hammond, 1982). Half chose to discontinue chemotherapy and half elected to continue chemotherapy for another two years. Parents participating in a clinical trial know that they were not locked into a protocol and could refuse randomization. They were aware also that a study objective was to minimize the duration of therapy and to diminish potential late effects of chemotherapy. Those electing to discontinue therapy decided that if the doctors consider it safe to randomly discontinue therapy after two years of CCR, there was no compelling reason to continue the inconvenience, expense and side effects of chemotherapy for another year or two.

Physician bias can influence the parents decision as well. Earlier studies suggested that the relapse rate off therapy in males was higher than in females (Sather, Miller, Nesbit, Heyn, and Hammond, 1981). Despite the higher death rate in patients relapsing while on therapy, some physicians and parents expressed reluctance in stopping therapy and running the risk of relapse. In a more recent trial in which patients were randomly allocated to one of three regimens: discontinue, continue for two more years, or reinduction, then discontinue, no significant differences were observed in disease-free survival of randomized or unrandomized patients in any of the three groups (Miller et al., 1982). A negative testicular biopsy was required in males prior to randomization but despite this precaution, relapses off therapy in males were higher than in females although survival was similar. Knowledge of this type is important to allay guilt feelings in parents who may refuse randomization and pick the "wrong" regimen. Yet, premature disclosure of the preliminary study results may bias the physician and the parent. For this reason, many controlled trials "blind" the treatment regimens so that the clinical investigator, when provided with an update of study results, is given coded regimens. If indeed there are no differences to date in the treatment regimens, he should so state to the parents. Premature closure of a study is poor science.

In summary, improved survival concomitant with participation in clinical trials has resulted in a modification of parental

adaptive behavior with a greater emphasis on optimism and hope. In depth studies of the psychosocial implications of participation in clinical trials have not been performed, but it would appear that parents are more informed, communicative, involved and less fearful of questions. Multidisciplinary teams comprised of pediatric oncologists, nurse practitioners, clinical psychologists, and social workers have improved the continuity of care in patients enrolled in clinical trials.

Psychosocial Stresses in Siblings

The once forgotten family member, the sibling, is receiving more attention and evaluation. Earlier studies, performed in siblings of patients dying of cancer showed that half had symptoms of enuresis, headaches, abdominal pain, school problems, depression and separation anxiety during the illness and an increase in severity after the patient's death. Recurrent themes were rejection, responsibility for death of the sibling, fear of dying and lingering resentment directed towards parents for preoccupation with an inability to protect the affected child (Cain, Fast, and Erickson, 1964; Binger, 1973). Determinants of behavior problems included the nature of death, the age, and character of the dead child, developmental level, siblings involvement in the death, parental communication, understanding and knowledge of illness, relationship to the dead child, immediate impact of death on parents, effect on family structure, availability of support, and concurrent family stress (Cain et al., 1964; Wiener, 1970). Younger siblings were at greatest risk and developed regressive behavior, resentment, psychosomatic symptoms, accident proneness and school phobia. Older siblings displayed a reactivation of rivalries developed at the time of the sick sibling's birth (Lindsay and MacCarthy, 1974). In a study of siblings of 60 patients with leukemia reported by Lavigne and Ryan (1979) siblings were more fearful, inhibited and withdrawn than healthy controls. Male siblings in the 7 to 13 year age group had more problems than females.

Gogan, Koocher, Foster, and O'Malley (1977) Gogan and Slavin, (1981) interviewed 101 siblings of 117 survivors of cancer whose diagnosis was made at least five years previously. All were older than the affected sibling and were interviewed a median of 13 years after the diagnosis. Not unexpectedly, the siblings understanding of the potential fatal nature of cancer increased as a function of the siblings present age and age at diagnosis. Only 20% had a "good" level of understanding of the disease and its implications, 58% had an average understanding, and 22% had a poor understanding. The impact of a cancer diagnosis was minimized at the time of diagnosis and was probably a reflection of the parents' reluctance to communicate the gravity of diagnosis when prognosis was poor. This cohort had no remembrance of feeling abandoned, described some rivalry but little guilt and believed that the patient, but not

they had changed. These retrospective self-evaluations suggest a more comfortable, less stressful reaction than when patients die of cancer.

Townes and Wold (1977) stressed the importance of parental communication. The oldest group of siblings received the most information and had a better understanding of the life threatening nature of the patient's disease. Closed communications in families contribute to the development of emotional and behavior problems in siblings of cancer patients. It is now recognized that siblings must be provided with direct factual information at the time of diagnosis, and during therapy to ameliorate or prevent adjustment problems. The sibling should be an integral part of the whole family approach to treatment and acknowledged as an important participant in the family's life throughout the illness (Cairns et al., 1979; Grogan and Slavin, 1981; Lavigne, 1980). As with parents, the psychotherapeutic approach with siblings has shifted from anticipatory grieving (Feinberg, 1970) to greater participation and involvement throughout all stages of the disease (Sourkes, 1980).

Experimental Therapy

Let us shift emphasis to the 40 to 50% of children who will die of cancer. Generally, these are children with poor prognosis ALL; ANLL: Stage III-IV non-Hodgkin's lymphoma; unfavorable histology Wilms' tumor; Stage IV neuroblastoma; rhabdomyosarcoma, and bone sarcoma; medulloblastoma and any child whose disease recurs while on active treatment. Early treatment failure and/or metastasis is invariably associated with early death, despite aggressive multimodality retrieval therapy with conventional or experimental approaches. What realistically can be expected from experimental or developmental therapeutics? What is the impact of experimental therapy on family members?

Retrieval therapy in previously treated children with ALL induces remissions a second time in approximately 60-90% of the patients. Median duration of remission is generally less than one year and fewer than 10% of patients are long-term survivors. Subsequent relapses occur more quickly, remission duration is shorter, extramedullary (CNS, testicular, pelvic) disease may occur and the patient becomes not only refractory to previously utilized conventional agents, but also severely immunosuppressed and myelosuppressed. Parents at this stage are faced with perhaps their most difficult decision--either to discontinue all specific anticancer therapy or to attempt prolongation of life (and possibly suffering) through newer modalities of therapy including Phase II and Phase I agents, and bone marrow transplantation.

Fewer than 25 to 30% of late stage patients achieve a remission or partial response with Phase II combinations or single

agents for which toxicity and drug dosage were established in Phase I trials. Cancer centers vigorously pursuing clinical research programs have a long tradition and commitment to experimental and developmental therapeutics. Every effective agent in use today was at one time an experimental drug. Responses in late stage patients are generally short-lived and less frequent than in previously untreated patients. Tolerance to chemotherapy is diminished, nutritional status is poor, antibiotic-resistant infectious disease complications are common, and refractoriness to blood component therapy adds to the difficulties of supportive care. Parents and siblings are exhausted physically, emotionally, and financially, recognize that long range success is impossible and yet elect to pursue experimental approaches. This zeal is not seen at the community hospital level where experimental modalities are not available. At our institution 120 patients per year of a total of 1000 under care for cancer are entered on Phase I/II chemotherapy trials. On the one hand, hope is offered, but on the other, experimental chemotherapy may enhance the parents' unrealistic expectations, rekindle denial and inappropriate demands and in some cases bring into focus long standing conflicts between mother and father regarding therapy and prognosis. In our experience mothers have been more accepting of reality and prognosis in children on experimental therapy, but these are clinical impressions that have not yet been subjected to evaluation and testing.

Entry on a Phase I/II trial implies that intensive supportive care will not be withheld during the period of drug evaluation. Thus, liberal use of blood component therapy, often supplied by parents and siblings, antibiotics, total parenteral nutrition, central nervous system prophylaxis with intrathecal chemotherapy, respiratory intensive care including respirators for pulmonary complications are all offered to the patient in an effort to complete the prescribed drug trial and permit full evaluability. Life-threatening complications, short of the truly catastrophic, are usually treated vigorously, but generally patients are not resuscitated and supported with respirators if, after an adequate trial of a drug, no response, or progressive disease has occurred.

On the slim thread of hope that their child might have a transient response and then be eligible for bone marrow transplantation from an HLA/MLC compatible sibling, most of our parents consent to at least one and occasionally three or four experimental drug trials. Because of severe toxicity, patients often remain hospitalized for the remaining month or two of their lives. Parental reactions are varied. Some, resigned to the inevitable death of their child, transfer responsibility to the medical-nursing staff, become totally detached and relieved of the burdens of decision making. Others rekindle intense feelings or disillusionment with the staff and display anger and anxiety. Ambivalence about their child's death fluctuates daily. Uncertainty is

fostered by the medical staff whose goal is to demonstrate effectiveness of the new agent. Great significance is attached to minor fluctuations in blood counts, fever, and bone marrow cellularity or lymphoblast percentages. Other parents, accepting the death of their child after seeming failure of the new agent, have made funeral plans and informed their families of the impending death of their child, only to get a reprieve induced by a partial or even complete response to the new agent being used.

Although rare, the Lazarus syndrome or seeming miracle is a fallout of Phase I/II therapy (Easson, 1981). Yet another paradox is the financial investment in what appears to be a hopeless cause, an issue rarely verbalized but certainly a cause for stress. Prolonged absence from work, separation from other children, disintegration of family structure and rifts between mother and father concerning treatment or no treatment place unimaginable stress upon the family unit already at the limits of endurance. Contrast this end to that described by Armstrong and Martinson (1981) in children dying at home. Despite the trauma associated with Phase I/II therapy, hope and prolongation of life remain driving forces in parents of children with cancer. Generally through direct communication and frank discussions with the responsible physician, limits are finally drawn regarding further specific therapy and supportive care. Accordingly, fewer and fewer patients are inappropriately transferred to intensive care units, needlessly resuscitated and kept alive for a day or a week after failure of even experimental therapy.

Although parents may have consented to a new drug trial, they exercise control again at the time of autopsy. Autopsy rates in childhood cancer have declined in our institution from 70% to 40%, reflecting a national trend. Having agreed to maximal involvement in clinical research, parents draw the line at the autopsy, reestablish control of their child's destiny and take command of the bereavement process.

Bone Marrow Transplantation and the Family

Bone marrow transplantation is now an accepted, effective and specific therapy of acute leukemia in children. In fact, current studies have shown that children with ALL transplanted in remission after a first or subsequent relapse have a 50% chance of survival as opposed to a 10% chance or less if relapse occurred during therapy (Thomas, 1981). In acute nonlymphoblastic leukemia, children and young adults with HLA-identical, MLC-compatible siblings are now being transplanted in first remission with encouraging preliminary results, considering the fact that with the best available chemotherapy, only 35% of children with ANLL will survive three or more years after diagnosis.

Although the physical and psychological impact of transplantation upon the patient have been studied extensively, virtually no data are available regarding the acute and chronic psychosocial effects of bone marrow transplantation upon the donor (usually a sibling), and the nuclear family. Despite the existing stresses swirling around the family at the time of diagnosis, no conceivably greater stress or sacrifice can be demanded of a family member when he or she is asked to serve as the donor of bone marrow. For the sibling-donor, attempting to cope with his own feelings of anger, guilt, resentment and isolation, the direct involvement in therapy and his commitment--the donation of part of his body to the afflicted sibling--add a new dimension to family interactions. The donor's role is changed from passive sibling to active savior.

Although the incidence of graft-rejection is extremely low, a major complication of bone marrow transplantation is graft-versus-host (GVH) disease in which immunologically competent lymphocytes from the donated marrow attack "foreign" tissues of the host leading to skin abnormalities, liver dysfunction, gastrointestinal disturbances, pulmonary involvement and bone marrow failure. GVH disease, with varying degrees of severity, occurs in 25% of transplanted patients. Although only anecdotal information is available, it is obvious that fatal GVH disease in the recipient would have profound psychological effects upon the sibling-donor and his parents.

Psychosocial intervention prior to, during, and after the transplant procedure must be anticipated and should be provided to the nuclear family unit. Similar problems would be expected in the absence of GHV disease, but during other times of medical crises following the transplant, the two most important being interstitial pneumonia and leukemic relapse. Leukemic relapse in the donor cells has been reported in four children undergoing bone marrow transplantation (Thomas, 1981), suggesting the transmissibility of a leukemogenic factor from host to donor transplanted hematopoietic cells or genetic predisposition of donor cells to leukemic transformation. None of the donors developed leukemia and although psychologic issues were not discussed, the psychodynamics of the donor whose transplanted sibling died of GVH disease, or leukemic relapse are worthy of study. Although supportive care, modifications of total body radiation programs, and better cytoreductive therapy prior to the transplant procedure may decrease the incidence, morbidity, and mortality of these complications, the impact on the donor is tremendous, must be recognized and appropriate supportive care must be provided.

Newer experimental techniques in transplantation biology have permitted transplants across the HLA-MLC barrier. Using soy bean lectin, it is possible today to separate immunocompetent, GVH-producing lymphocytes from hematopoietic stem cells in the bone

marrow. Successful "lectin-separated" transplants have been done in children with severe combined immunodeficiency disease and the technology is now being applied to children with ALL who have had multiple relapses. Donors for lectin-separated transplantation are generally parents. This procedure is reserved for children who have an extremely poor prognosis or who have failed conventional therapies and are receiving experimental agents. Parents unaware of the availability of the procedure, slowly accept the eventual fatal outcome in their child. New agents offer some short-term hope for transient remissions and extension of life to a birthday or Christmas, recognized fatefully as the last. The interjection of the possibility of a bone marrow transplantation whether it be from a sibling or parent rekindles a last-ditch effort to save the child's life. Massive energy is exerted having all available family members tested and retested to find the "ideal" donor. Contacts may be made with an HLA testing laboratory in London, where an HLA-compatible potential donor may be found in the data base. These efforts are usually fruitless, and create false hopes. Unless a massive program is undertaken in the United States to register and computerize HLA data on millions of potential bone marrow transplant donors, extension of the search beyond the family is generally not practical. The extent of parental involvement in such experimental approaches is illustrated in the following vignette.

> Sandy G. was an 11-year-old girl with average prognosis ALL diagnosed in 1977. Her father was a cardiologist, her mother a nutritionist. Both were extremely knowledgeable, read compulsively about leukemia, religiously attended parent group meetings, and exerted a firm control over decisions concerning procedures and treatment. She was entered on a national protocol study and randomized to receive standard therapy. She remained in complete continuous remission for three years and although the protocol called for randomization to either discontinue therapy or continue therapy for two more years, the parents predetermined that if her bone marrow and spinal fluid examinations were normal, therapy would be discontinued. One month before the anticipated three year date, she developed neutropenia, necessitating discontinuation of therapy. Her blood counts never recovered and her bone marrow revealed frank relapse, but with a suspected phenotype change from ALL to AUL.
>
> She was successfully reinduced with an intensive treatment program, but relapsed again four months later. A third induction attempt was partially successful. Her 7-year-old brother was not HLA-MLC compatible and despite testing at least 20 family members, no acceptable matches were found. Despite an all-out four

month effort, potential donors in the Seattle and London data bases were not found. The family was offered a lectin separated marrow transplant with father as donor. Although Sandy was in relapse, the procedure was carried out after she was given an aggressive cytoreduction program and total body irradiation. Three days after the transplant, she developed severe congestive heart failure requiring intensive cardiopulmonary supportive care. During the child's last three weeks of life, father remained in the Bone Marrow Intensive Care Unit, donated platelets and granulocytes, and assisted in her cardiopulmonary care. An autopsy showed cardiomyopathy, pneumonia, severe hemorrhagic cystitis, hepatic engorgement, hypoplastic marrow, but without evidence of leukemia. It is unlikely that a parent could conceivably be more immersed in supportive care than Dr. G. was. The family cancelled a follow-up appointment to review the autopsy findings, but a report from the referring pediatrician who is a close friend, indicates that the family is intact and coping well.

Terminal Stages of Disease

The impending and actual loss of a child by death is emotionally devastating. Parents may be prepared for the eventual death of their child, but the medical efforts to utilize new agents, extend durations of remission, and support life with advanced technology introduce glimmers of hope where indeed there is none. The answer of most parents when asked why they participated in an experimental drug or treatment program is simply "because we wished to do everything we could to prolong her life." In a sense, parents transfer the responsibility of success or failure to the medical support team. Rarely do parents state that they "wished to help medical science" or "help another leukemic child." However, the number of experimental agents, the child's tolerance to chemotherapy, and the parents' ability to witness the progressive deterioration of their child are not infinite and, on occasion, parents will choose to withhold any further chemotherapeutic agents. The worst possible situation is the callous and inaccurate statement by the physician "there is nothing more I can do." The obligations inherent in providing appropriate supportive and comfort care to terminally ill children preclude this negative statement of withdrawal.

Tremendous pressure and stress are placed upon parents after a decision is made to withhold further chemotherapy. Options for further supportive care could range from passive euthanasia with discontinuation of all blood component therapy, antibiotics, and

total parenteral nutrition to denial of the inevitable and continued intensive medical management. When lines of communication have been open throughout the various phases of treatment, parents who are prepared for their child's death can openly participate with the medical and nursing staff in decisions to discontinue selected components medical support that may sustain life, but offer no comfort or hope for cure.

As the child's illness progresses, the likelihood of miscommunication, anger, and frustration increases. An expression of the frustration is to blame others for problems in care. The presence of pain increases distress for parents who take on the role of protector to obtain relief for their child. The trade off between oversedation and tolerance of pain to remain alert is difficult to maintain in ideal balance. This and other critical decisions must be shared by the parents and physicians with primary attention, maximal support, and comfort the rule. Parents who have been partners in collaborative clinical research and trust the medical staff are very likely to share decision-making at the end of the disease just as they did at diagnosis.

Anger, resentment, hostility, and litigation following the death of a child at a cancer center are less likely when the multidisciplinary team and the primary physician are open, frank, honest, supportive, and available not only during complete remission, but also during the terminal stages of disease (Spinetta, 1981). Not only parents, but also physicians suffer from premature withdrawal from the dying child. Strong, open, well-prepared parents achieve a peace and understanding regarding their child's impending death, can talk to their child about it, discuss it with staff and frequently take over the leadership role in the emotional supportive care aspects of the terminal phase of disease.

Young residents, fellows, nurses, and ancillary staff cope poorly with the high death rates on a children's cancer ward and psychosocial support for the staff is as vital as it is for the patients and parents. With some parents who have accepted death, grieving is accomplished ante-mortem and the child is discussed in the past tense, often in his presence. With advances in medical technology and the ability to postpone the event of death, children and parents may be in the "living dead syndrome" for days and weeks.

Factors which contribute to the adaptation of the family are the cultural context in which it operates, availability of social supports, the nature and type of pre-illness family function, and the developmental stage in which the family unit is functioning (Holland, 1982). The beliefs and attitudes of the social group (family, friends, clergy) surrounding the family can have a profound influence on the parents' reactions and actions during the terminal phase of illness during which time they are particularly

vulnerable to unconventional therapy, quackery and unproven methods. Most are suggested by caring, well-meaning family members who feel duty-bound to mention all possible known cures to the desperate parents (Faw, Ballantine, and Van Eys, 1977). At the MD Anderson Hospital, 27 of 69 (39%) of parents interviewed had tried, considered, or received recommendations to try unproven remedies including laetrile, dietary concoctions, minerals, vitamins, vaccines, and assistance from faith healers. Parents most susceptible to quackery are those feeling most hopeless and helpless, and willing to accept any advice or suggestion that alters the prognosis and offers cure. Physicians can drive parents to unorthodoxy by intolerance, intimidation, refusing to discuss their questions about the role of unproven remedies or even threatening to sever all caregiving. Parents who sense the emotional support of the physician and the health care team are less likely to seek alternative therapies than parents who sense a lack of concern and commitment from the medical staff.

Although the courts have upheld that parents cannot withhold proven effective therapy from a previously untreated child with leukemia or other cancer in which there is some chance of cure, legal action against families seeking unconventional therapy during the terminal phase of illness is a cruel exercise in futility particularly when the available therapy offers virtually no chance of cure.

The popularity of nutrition reflects the parents desire to exert some control and direction over the disease through a holistic approach (Holland, 1982). The arguments of the proponents of quackery are particularly appealing to parents without hope for cure through conventional medicine. They raise the spectre of a cancer establishment conspiracy, consciously withholding effective therapy from cancer victims. Their propaganda forum is the media, not the scientific journal or meeting. They condemn controlled clinical trials and prefer faith and conviction rather than p values. Parents are seduced by current trends in free choice, holistic medicine and mind-body unity. The physician himself may drive the family to a laetrile clinic or to coffee enemas. The risk is heightened when parents sense the physician's sense of failure, as illustrated in the following vignette.

> Andrea was an 8-year-old girl from the Virgin Islands with AML, who achieved a complete remission after three courses of intensive induction complicated by Gram negative sepsis requiring massive supportive care and a five-week hospitalization. She remained in remission for eight months on a maintenance program requiring four days of outpatient chemotherapy monthly. Her 6-year-old brother was not HLA-MLC compatible. Partial remission was achieved with a combination of daunomycin and cyclo-

cytidine at which time the physician proposed a Phase II clinical trial. In answer to the critical question, "Will this drug combination cure our child?", the physician replied "although there is a good chance that she'll achieve remission, it's unlikely that this drug or any others we now have can cure her." The family rejected the Phase II therapy and the physician then proposed that they return home where she could receive supportive care without chemotherapy, but at least be in familiar surroundings for the rest of her life. The parents rejected the idea, discharged the child from clinic and spent six weeks at a "health farm" in southern California where Andrea was treated with diet, minerals, and vitamins based upon salivary and urine pH. She remained in partial remission, but required periodic blood transfusions. When disease progression was noted, the family flew to Jamaica in the West Indies and received a course of laetrile and immunotherapy. Andrea got sicker and the family flew to Birmingham, Alabama, where she was admitted to a private clinic to receive a new leukemia vaccine. She died on Christmas eve in Alabama. The family is intact, but six years after the death of their daughter, have little faith or trust in the medical profession. Each of the private clinics had told the parents that their therapy was curative, but that they had gotten there "too late." The first eight months of her treatment were considered critical. This wasted time they felt was responsible for her eventual death.

Physiological Consequences

Terminal cancer in a child increases the levels of stress in family members with dysphoric symptoms of depression, anxiety, anger, and frustration. Increased hypothalamic, pituitary, and adrenal activation correlates with emotional distress and is a quantifiable physiological consequence of childhood cancer. Wolff, Friedman, Hofer, and Mason (1974) measured psychoendocrine responses in 31 parents whose children died after a fatal illness. Urinary 17 hydroxycorticosteroid (17-HCS) excretion was measured throughout the illness and was lower in parents who developed adaptive behavior and who had less overt emotional distress. Furthermore, parents with prolonged active mourning responses and emotional distress after the death of their children had the highest levels of 17-HCS (Hofer, Wolff, Friedman, and Mason, 1972). In studies performed in adults with cancer, it appears that the pattern of psychoendocrine response remains relatively constant for each individual over prolonged periods of observation (Gorzynski, 1980).

Immunologic dysfunction is also associated with the grieving process. In humans, depressed lymphocyte function in mourning in widows (Bartrup, Lazarus, Luckhurst, Kiloh, and Penny, 1977) and in husbands whose wives died of breast cancer (Schliefer , Keller, McKegney, and Stein, 1980) have been detected. In animals, studies suggest that the immune state is responsive to the emotions. Stress causes an elevation of corticosteroids, lymphopenia, and thymic involution. Survival was shortened in stressed animals after inoculation of tumor (Riley, 1975). In chronic stress T-cell activity is acutely suppressed followed by transient enhancement (Monjan and Collector, 1977). Both studies support the hypothesis of neuroendocrine control of immune functions (Fernandes, Caradente, Halberg, and Good, 1979). Further support was provided by Ader and Cohen (1977) who showed that immunosuppression can be induced in animals by conditioning, but was not related to alterations in cortisol levels (Bovbjerb, Cohen, and Ader, 1979).

With the improved prognosis in childhood cancer, it will be necessary to repeat or expand these studies at the time of diagnosis during periods of crisis, in the terminal phases of disease, and after death.

The Media and Clinical Research

As if the diagnosis of cancer itself didn't produce enough stress, the impact and tone of the media with regard to clinical research has unwittingly or consciously exacerbated the existing stress. Typical examples include the thoughtless press releases announcing a "new breakthrough to cure leukemia" initiating parental responses of doubt, indecision, anger, frustration and false hopes depending upon their child's disease and clinical status. Many of these reports are preliminary and premature, involving mice, not patients, and are probably one or two years away from a Phase I clinical trial. Frequently, parents will request the use of a new, unproven agent (e.g. interferon) following glowing reports in the press and on T.V. despite the fact that their child is in a long sustained complete remission on a standard treatment protocol. The new, dramatic and exciting make news. Carefully controlled meticulous trials are not newsworthy.

More malicious were a series of articles by Gup and Neumann in the Washington Post (October, 1981) reviewing and condemning the experimental drug program sponsored by NCI. The thrust was that experimental chemotherapy does more harm than good by killing more patients than are saved. They claimed that patients subjected to experimental chemotherapy "donate their bodies to science while they are still alive" and that "there were no 'safeguards or concern' for the patients receiving experimental drug therapy." They claimed that drugs cause irreversible side effects, enhance the growth of cancer cells, and even cause cancer. They stated that

"drugs shown to be useless are given years after their uselessness was demonstrated." Physicians involved in the use of experimental drugs did not escape either. They were accused of fatally miscalculating drug doses, exaggerating results, fudging records, having no concern for side effects, death, and suffering despite the fact that the chances of benefit were so remote. They questioned the methods of obtaining informed consent and suggested that many experimental drug studies were not approved by the FDA, further adding to a portrayal of the clinical cancer chemotherapist as a sinister, ghoulish and unethical practitioner of a black art. Unfortunately, recent scandals involving clinical researchers at Yale and Boston University have not helped the tarnished image of the physician-scientist. The critical point that every effective Phase III chemotherapeutic agent in use today was an experimental drug one, ten, or even 25 years ago and that these agents are responsible for the improved prognosis in childhood cancer escaped the authors.

Although this is not the appropriate forum to offer rebuttal to insensitive and irresponsible reporting such as this, I emphasize it because it is a continuing source of external anguish and distress to parents of children with cancer who are willing to pursue experimental approaches knowing fully that the alternative to no treatment is certain death. Generally, most parents accept the risks of experimental chemotherapy and choose life. Dr. Brigid Leventhal (1981) at Johns Hopkins University replied to the articles with sensitivity and spoke from the parent's perspective:

> "When the interview with you (Mr. Neumann) was finished the family was depressed. They had called you trying to get a point of view across. Don't forget they feel some responsibility for having their child participate in the trial, since they signed the consent form agreeing to it and they wanted to tell you the positive reasons they had for making that difficult decision. They wanted to tell you something about maintaining hope in a bright child whose tumor is growing and hurting him. They wanted to tell you something about belonging to a 'family' of people with a particular disease and trying to help those people coming along after their child by agreeing to a test of a new drug. They wanted to tell you something about working as a team with the physicians who were looking after their child and making decisions together while facing extremely difficult, and, in the end, insurmountable odds. They wanted to tell you something about their child not having died in vain. And they had the impression that you were trying to get them to say something critical which would appear to diminish the value of the drug trial...

Don't forget, we are all pretty sad when it comes to the death of a child. It doesn't take much to hurt our feelings further or get us more depressed."

Coping with childhood cancer is certain to be the most devastating experience of a lifetime for parents. Clinical research has improved the outlook in children and today's experimental drug may become tomorrow's standard therapy. Cancer treatment is not static and never will be. With continued progress, virtually all children with cancer will be cured. Clinical research will continue to make major contributions to this progress.

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DOCUMENTATION OF EFFECTIVENESS OF PSYCHOSOCIAL INTERVENTIONS: DISCUSSION OF DR. MILLER'S PAPER

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The clinical research treatments of childhood cancer present an impressive array of achievements, but an equally impressive array of consequent medical and psychosocial problems. The change in the five or more year survivor rate in acute lymphocitic leukemia (ALL) is indeed impressive: before 1966 only 10-15% of children survived five years, whereas now 95% can expect an initial remission, and as of 1975 60% survived more than five years. Further, most solid tumors have similarly responded: in the 1950s less than 20%, whereas in the 1970s 60-80% survived disease free. Miller emphasized that the refinement of treatment protocols that contributed to this change were only possible through multicenter clinical research trials using random patient assignments.

Miller states: "Participation in a clinical research protocol has placed additional burdens and stresses upon patients, parents, siblings, and physicians, but, from available data, the benefits in terms of improved survival, communication, and understanding of disease outweigh the risks." Miller balances this optimism with the acknowledgement, "We know very little about the emotional/psychological effects of experimental chemotherapy and bone marrow transplantation upon the patients, family, and physician." Miller reviews the rather sparse studies on psychosocial coping: as late as 1973 most work emphasized the need to help deal with issues related to death and dying. Indeed, most of the studies comparing good and bad copers, emphasized the need to comprehend the fatal outcome, the ability to grieve, etc. as key issues in the adaptive process. Miller emphasized that because of the change in prognosis in the last few years, that "optimism, hope, and an affirmation of life" rather than death are emerging as the key variables in the new prognosis era of childhood cancer.

Unfortunately, in the survivors the late effects of combined modality cancer therapy are indeed awesome: organ dysfunction, permanent physical disfigurement, growth and secondary sexual development delays, neuropsychological dysfunction, and second malignant neoplasms related to chemotherapy and radiation therapy, to which must now be added a high incidence of psychosocial dysfunction (Koocher and O'Malley, 1981) are a partial list.

It is most unfortunate that no information was included that describes either the psychosocial effects of these treatment complications, or of the responses to various psychosocial interventions with two exceptions: one is Koocher's survey of survivors (Koocher, this volume), the other is the recent interest in neuropsychological sequelae in ALL survivors (Press, this volume; Christ, this volume).

Because of the recent changes in the prognosis of a number of the childhood cancers, and the high risk for treatment induced late effects, Miller emphasizes the need for many of the parents to involve their children in a randomized series of treatment protocols to determine whether some combinations will yield better results with less serious iatrogenic side effects. This option poses a new difficult choice for parents and youngsters: he finds that few parents reject the offer of participating in such research clinical protocols. Indeed, in the past four years 100% of ALL diagnosed youngsters at Memorial Sloan Kettering Cancer Center have been enrolled in such clinical randomized protocols. The informed consent form is a fair explanation of the procedures and risks, and, as Miller points out, is in itself a source of stress.

The need for psychosocial interventions and support is stressed; however, only parent support groups are identified by Miller. Unfortunately, controlled studies to determine what type of support or psychosocial intervention is helpful or optional are not cited, and seem not to have been done. Information on the siblings of the cancer patient is quite sparse, and not really interpretable. Since the incidence of some form of emotional difficulty in children and adolescents has been estimated as from 5-25% in the population, it is essential that statements about behavioral difficulties be accompanied by some estimate of frequency, and with a comparison if not a true control group to insure that the behavioral difficulties are truly significant beyond the expected frequency.

Miller next reviews the impact of experimental drugs after standard treatments have failed. Now the tasks are quite different: the chances of even short remissions are greatly reduced, the emphasis now truly shifts to the preparation for the inevitable death. Great emphasis must now be placed by the medical staff on life-support and comfort enhancing measures. The physician's rejection of the "hopeless" patient or giving up the intensity of his involvement with the child and family can precipitate great

distress, and enhance search for miracle cures.

A special area, one that has recently shifted from experimental to accepted, is bone marrow replacement. Miller reviews what are unfortunately only anecdotal statements about the reactions of the donors, usually parents and siblings. The high incidence (25%) of graft-versus-host disease mark this as another area that cries out for systematic assessment of the emotional impact with either life or death on the donor.

At this time of increased availability of life support measures, there are indeed nearly infinite decisions that need to be made once death appears clearly imminent. Miller reviews some of the stresses the parents must endure as they make decisions to discontinue selected aspects of the supportive treatments. Miller clearly outlines the great need for refined support, not only of patient and family, but also of hospital staff during this stage of treatment. Perhaps more than any other, this is the time the oncologist's true competence as a humanitarian physician rather than as a well trained technician is called upon. Treatment is still called for even if cure or the possibility of cure are not there. The potential for "miscommunication, anger, and frustration" is perhaps at its greatest at this stage.

Finally, Miller describes the destructive impact of "malicious media reports." It would appear that reporters aid and abet our cultural need to find a culprit when diseases are frightening and terminal. From the clinician's perspective, printed statements like "experimental chemotherapy does more harm than good by killing more patients than are saved" is at best a misstatement on the basis of inadequate information, at worst a rabble rousing effort to sell more newspapers. Unfortunately, the reporters probably tap into the general nonacceptance of the inevitability of death, and the naturalness of disease as a consequence of life. Such a fatalistic perspective is alien to this culture. More palatable is to look for a palpable culprit whom one can blame for the death.

Clearly, cancer patients have major psychosocial problems--some a concomitant of the disease, others of the treatment and the research endeavors. Interventions aimed at enhancing the coping capacity of their youngsters and their families are available. Their effectiveness must be documented by carefully designed and controlled studies.

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THE STAFFING CONFERENCE IN PEDIATRIC ONCOLOGY[1]

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I. INTRODUCTION

Cancer in children is a very different reality now from what it was only a few decades ago. Instead of cancer being an invariably fatal disease, it is now a disease in which biological cure is the norm. The long-term survival rate varies among cancers, but the overall cure rate approximates 60%. One in 600 children between birth and 15 years of age acquires some form of neoplastic disease (Young and Miller, 1975). Therefore, in approximately 10 years, one in 1000 individuals reaching the age of 20 will be a survivor of childhood cancer and its therapy (Meadows, Krejmas, and Belasco, 1980). We must, therefore, be concerned not only with effective therapy but also with the effects of our therapy. There is a significant medical cost of cure and that cost should be taken into consideration in designing new therapies. However, there is also a documentable psychological cost of cure (Zwartes, 1980).

Children with cancer are faced with multiple threats to their psychological well-being in a complex set of intertwined medical, emotional, and social variables. Psychological support in life-threatening illness has traditionally been interpreted as ongoing management of pressures from ontological concerns in patients and families separate from, but in conjunction with, management of the equally enormous social and economic impact of our mode of care (Cairus, Clark, Black, and Lansky, 1979).

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When cure is the norm, however, the long-term psychological consequences must also be taken into account and incorporated into the design of new therapies. The physical handicaps that result from our therapies, which frequently still are mutilative, can be overcome. But if the child is not mentally healthy and cannot perform at an age appropriate level in society, we do not have a child who is functional, who is not a "truly cured child" (van Eys, 1979a).[2]

To achieve that truly cured state, we should have a patient who is at ease with having had cancer. There is a more profound handicap from psychological maladjustment than is ever generated by physical incompleteness. Children and parents must consider it normal to have had cancer. Cancer is no different a disease in concept than are other chronic illnesses. It is normal to have cancer. A child who has cancer is normal. There is a norm for a child who has cancer and a normally sick child with cancer is still a child (van Eys, 1979b).

To generate a total care plan aimed towards a truly cured child, in an environment in which having cancer is normal, coordinated and individualized planning is necessary. This planning has a strong conceptual analogy to the planning mechanism embodied in the educational programs for the handicapped. This paper will briefly review this conceptual and practical analogy. Our approach through the staffing conference and the consequent individualized treatment program will be described and some of the impact and results will be briefly presented.

II. THE THEORETICAL FRAMEWORK

There is an analogy between the reintegration of the medically exceptional child and the acceptance by society of the child with cancer as cured. Only when that is achieved can the child feel self-acceptance and realization of full potential. The right to education for a handicapped child is a concept that only recently has been accepted. The original approach in special education was to generate environments that resulted in a segregation and labeling of the child, not unlike the consequences of de facto racial segregation. Yet, it was done with the intent to generate an environment in which special skills could be brought to bear on the child. In a landmark address to the Council of Exceptional Children,

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[2]Many references pertain to our annual mental health conferences. These conferences are in a sense staffing conferences for the whole therapeutic community, wherein our yearly individualized programmatic plan is examined, reaffirmed, and refined. Parents, patients, and all professional members of the therapeutic community participate freely.

Dunn questioned this separate approach and suggested the concept of mainstreaming for the mildly retarded child (Dunn, 1968). A sequence of developments followed through academic evaluation of the problem, several landmark legal actions, and finally, legislative attention. A major step was Mills versus Board of Education of the District of Columbia, in which the court adopted the concept that every child, no matter how severe the handicap, must receive suitable, publicly supported instruction.

> The District of Columbia shall provide to each child of school age a free and suitable publicly supported education regardless of the degree of the child's mental, physical or emotional disability or impairment (Mills, 1972).

This step clearly indicated a complete change in attitude of acceptance of the handicapped child as any other child. Congress recognized this attitude change by passing into law a series of acts: The Vocational Rehabilitation Act of 1973 (1973), the Education of the Handicapped Act of 1974 (Public Law 93-380, 1974), and finally, the Education for All Handicapped Children Act of 1975 (Public Law 94-142), which is an amendment to Public Law 93-380 (1975). In Public Law 94-142, it states:

> It is the purpose of this Act to assure that all handicapped children have available to them...a free appropriate public education which emphasizes special education and related services to meet their unique needs, to assure that the rights of handicapped children and their parents or guardians are protected.

Only in 1980 did this law, which recognized access to public school education, become a practical reality. The method of implementation of the law indicates the method by which the introduction of the child with cancer into society can be accomplished. The analogy is more than trivial. The concept used to be prevalent that cancer leads to a handicap. However, the true situation is that having cancer <u>is</u> the handicap that must be dealt with. The White House Conference on Handicapped Individuals (1977) adopted a resolution affirming that concept.

To generate an appropriate education for the child, the concept of a least restrictive environment was introduced. This affords handicapped children equal access opportunity to the environment that is most appropriate to their academic, social, and emotional maturity. When we change "academic" to "medical," we have the equivalent statement for the child with cancer.

The heart of the law is the IEP--individualized education program. To quote the law:

> The term "individualized education program" means a written statement for each handicapped child developed in any meeting by a representative of the local educational agency or an intermediate educational unit who shall be qualified to provide, or supervise the provision of, specially designed instruction to meet the unique needs of handicapped children, the teacher, the parents or guardian of such child, and, whenever appropriate, such child, which statement shall include (A) a statement of the present levels of educational performance of such child, (B) a statement of annual goals, including short-term instructional objectives, (C) a statement of the specific educational services to be provided to such child, and the extent to which such child will be able to participate in regular educational problems, (D) the projected date for initiation and anticipated duration of such services, and (E) appropriate objective criteria and evaluation procedures and schedules for determining, on at least an annual basis, whether instructional objectives are being achieved (Public Law, 1975).

To achieve such an IEP, there has to be a conference during which the IEP is developed. This conference is generally known as an ARD (Admission, review, and dismissal) conference. The participants of the ARD committee, as indicated in the law and elaborated in the proposed regulations that accompany the law (and that have since been affirmed), include:

> The local educational agency shall insure that each meeting includes the following participants:
>
> (a) A representative of the local educational agency, or other than the child's teachers, who is qualified to provide, or supervise the provision of special education.
>
> (b) The child's teacher or teachers, special or regular, or both, who have a direct responsibility for implementing the child's individualized education program.
>
> (c) One or both of the child's parents subject to 121a.225.
>
> (d) Where appropriate, the child.

(e) Other individuals, at the discretion of the parent or agency (Federal Register, 1970).

There is strong emphasis in the law and regulations to insure the parents' participation. Section 121a:224 of the regulations (1970) reads:

(a) Each local educational agency shall take steps to insure that one or both of the parents of the handicapped child are present at each meeting or are afforded the opportunity to participate, including scheduling the meeting at a mutually agreed on time and place.

(b) If neither parent can attend, the local educational agency shall use other methods to insure parent participation, including individual or conference telephone calls.

(c) A meeting may be conducted without a parent in attendance if the local educational agency is unable to convince the parents that they should attend. In this case the local educational agency must have a record of its attempts to arrange a mutually agreed on time and place, such as:

(1) Detailed records of telephone calls made or attempted and the results of those calls.

(2) Copies of correspondence sent to the parents and any responses received, and

(3) Detailed records of visits made to the parent's home or place of employment and the results of those visits.

(d) The local educational agency shall take whatever action is necessary to insure that the parent understands the proceedings at a meeting, including arranging for an interpreter for parents who are deaf or whose native language is other than English.

The idea is not to get parents' permission, but to have meaningful participation. The IEP is "developed" during the ARD conference. The ARD conference is not to instruct the parents unilaterally. It is not the intention of the law that the parents simply have a reactive role, commenting on a program that has already been com-

pleted by the school or between the school and the child. The Texas Education Agency (1980, p. 4-5) stipulates the rights of the parents:

> In the admission, review, and dismissal committee process, the parent or adult handicapped student has the right to:
>
> be notified, within a reasonable period of time, when the ARD committee is scheduled to meet to make decisions about the student's special education needs and services.
>
> have the ARD committee meeting held at a time and place that is convenient to both the parent and the school. However, if neither parent can attend the school must use other methods to ensure parent participation.
>
> take someone with you to the ARD committee meeting to assist or represent you in the decision-making work of the committee and to take any other persons you feel may be helpful in advising you or your representative.
>
> know why a particular special educational placement was chosen over other placements.
>
> be actively involved in the ARD committee when the IEP is planned and written.
>
> formally disagree with the IEP including the determination of educational placement.
>
> give written consent before the student is placed in a program providing special education instruction and/or related services for the first time.

The impact of this program initiated by Public Law 94-142 on the education of handicapped children, on their future role in society, and on their demand on publically available resources is without parallel in the history of American society.

The new concepts that are raised by cancer as a curable disease are entirely analogous. There is a narrow application in that the cured child with cancer must reenter the educational system as a pupil with full expectations. That in itself is a major challenge for pediatric oncology. The child will be learning in adversity (Kalinowski, 1979; Zwartes, 1979), and will have many reentry problems, posed by self and school alike (Deasy-Spinetta, 1981).

However, the applications of the ARD-IEP system are much more profound. The questions raised by the planning for the child expected to be cured of cancer in a total cure environment are entirely analogous to the questions raised by the planning for the handicapped child expected to be functional in society. The child and parent must be full participants. The whole of the medical, nursing, and psychosocial resources must be brought to bear on a coordinated program to generate an individualized care program.

III. THE PRACTICAL EXPERIENCE

The therapeutic community. A child with cancer should be cared for in a therapeutic community composed of many participants. All have equal responsibility for the welfare of the child, but different tasks to perform to achieve the true cure (van Eys, 1979b). In order to achieve an integration of these complex tasks in our own hospital, two principles are held. First, each member of the therapeutic community is a member because of his or her special skills. If the child chooses you as a medical friend, that is the child's right. However, there is no a priori special place in the community because of that selection. Second, the tasks are divided into sets so that each child has a designated physician, nurse, and mental health professional. All other members of the community are placed in one or another of those sets (van Eys, 1980). Table 1 summarizes this work division.

Table 1

Staff Responsibilities

	Attending Physician	Designated Nurse	Responsible Mental Health Professional
Individual members of set	Fellows Residents Interns Nutrition/ dietary	Nurses Clerical Staff Pharmacy Chaplaincy Volunteers	Psychologist Social Worker Child life worker
Resources	Consultant service Administration	Housekeeping Central Supply	School teachers Volunteer services
Support	Diagnostic services Therapeutic services	Specialty nursing teams Discharge planning	Psychiatrist

Parents and children are a set of their own. Their participation makes the community have purpose. One of our patients summarized that need clearly:

> We should be fully informed and be allowed to participate in every decision; it is the patient's life that is being controlled. I know more about myself than the doctors do, and they should take my feelings into consideration (Harris and Stripling, 1980).

Each patient has some members of the total therapeutic community who especially influence his or her specific individual treatment program. Any conference that incorporates such a planning process will have certain fixed participants and additional members who might be of special need for that specific patient. Our institution has in excess of 300 new cases per year. As yet, a specific staffing conference (our ARD equivalent) is not feasible for each patient. We have to limit ourselves to a demonstration project.

The staffing conference. Each week, one patient and family is selected and invited to attend a meeting in which their case is discussed in depth. The cases are chosen from each of the medical services in turn, unless a particular issue in regard to a patient seems pertinent. Then that case takes precedence. This meeting is chaired by our clinical psychologist and attended by representatives of all the disciplines involved in that particular patient's care. These routinely include medical, nursing, mental health, dietary, child life, and chaplaincy personnel. In addition, when appropriate, school teachers are routinely present. Brief reports are first given by each discipline representative, and the family is interviewed and encouraged to ask questions and are considered as fully participating in the treatment planning for the child. At some point, the psychologist discusses with the family any issues that may need clarification or that might be sensitive for them. Their attendance is voluntary, and they may attend either all or part of the meeting. Almost all families, parents as well as patient and siblings, agree to come and most find it beneficial in some way. One child, for instance, expressed her frustration at not being allowed to help in her older sister's care except for being assigned household chores. After each staffing conference, a summary with recommendations is written and placed in the patient's chart. The meetings are audiotaped and the families are allowed to obtain copies of the tapes if they so desire.

During a two-year period between 1979 and 1981, nearly 100 staffing conferences were held. Table 2 summarizes the distribution by services. Ninety-one staffing conferences were patient oriented. In twelve, families were not present. The reasons for their absences are tabulated in Table 3. Some families had more than one reason.

Table 2

Distribution of Patients in Staffing Conferences 1979-1981

Leukemia service patients	30
Lymphoma service patients	15
Solid tumor service patients	11
Rare tumor service patients	15
Brain tumor service patients	17
Non-cancer disease patients	3
Subjects of topical interest	5
	96

However, it is notable that only five (5.5%) families refused attendance. In the one instance where the family was not invited, the conference members discussed how to handle the patient's grandmother (his guardian) who frequently became psychotic but refused psychiatric intervention.

In four cases, the child was too ill to come and for the parents to leave him, or medical treatments took priority.

One child had died several days previously, and the subject of the conference was a "psychological autopsy" (Weisman and Stripling, 1980) to review the family's extraordinary coping skills. The other patient died somewhat unexpectedly just before the conference and the meeting was used for the staff to express their own feelings to one another.

In the five cases where the families did not appear, four had agreed to the conference but simply did not attend. One did not wish to come from the beginning. In the two-year period, of those

Table 3

Reasons for Lack of Family Participation in Staffing Conferences (1979-1981)

Family not invited	1
Medical problems or tests prevented attendance	4
Death of child just prior to the meeting	2
Family did not wish to attend	5

approached, few have declined; in most cases this was attributed to shyness on the part of the families.

In the five conferences where the focus was on issues or on reaching general consensus on issues rather than patients and their individualized management, the following topics were discussed:

1. Middle class patients, not of the state or country, for whom the expense of medical treatment will seriously affect their financial situation with implications of years of indebtedness.

2. The psychological autopsy.

3. The role of psychology in the Pediatric Department.

4. Bone marrow transplants. Medical and psychological management.

5. Follow-up conference to discuss the group process of a previous conference wherein the staff joined the family in counterproductive denial.

Case example. Alan S., is an 11 year old boy with a pontine glioma originally identified in October, 1979. A staffing conference was held soon after diagnosis, with the primary focus on: 1) informing Alan about medical information, 2) his family's reluctance and uncertainty about this, and 3) on the family members' various ways of coping with the illness. Recommendations made at the first conference included: more open communication with Alan regarding his disease and treatment, genetic counseling for the family (Alan's uncle had recently died of a brain tumor), nutritional counseling, psychotherapy, and a more active role on the part of the father in Alan's care.

Nine months later, after a series of medical complications, another staffing conference was held for the purpose of assisting Alan and the family in making difficult decisions about further treatment and to support them during a time of great anxiety and uncertainty.

Alan's medical history after diagnosis of the tumor in the fall of 1979 was reviewed. He had radiotherapy treatment initially, but after only a transient response, four courses of the MOPP regimen were administered. This was still only partially successful. In May, 1981, high dose methotrexate was given, but two of the four courses were extremely toxic, resulting in temporary renal failure, mouth and intestinal sores, low blood counts, and infection. After recovery from the toxicity, two problems remained: poor nutritional intake and skin lesions in the rectal area. The nurses reported that their efforts with Alan had focused primarily on alleviating

the toxic effects of chemotherapy and on relating to Alan in an age-appropriate manner, allowing him as many choices as possible. They noted that Alan's reluctance to eat was associated with his distress about his appearance which had been altered by decadron, making him appear obese.

Three members of the Mental Health Division reported on their work with the family. The family is Jewish and moved to the United States from Cuba. The father was born in Turkey. All family members speak English fluently. The maternal grandparents live very near the family and assist them in managing their situation. The grandfather is a physician. There are two other children in the family, one girl older than the patient and one younger. The social worker noted Mrs. S's concern about meeting her obligations adequately. Her time was torn between attending to the patient, to the other children and to the family business. The child psychiatrist had been consulted to evaluate Alan with the possibility that psychotropic medication could be prescribed for the depression and withdrawal which were intensifying. Since antidepressants had not been thoroughly investigated in children, however, the recommendation was made for psychotherapy and behavioral management in lieu of medication. The psychologist's work with the family included hypnosis and relaxation techniques and family therapy.

The nutritionist reported on Alan's weight, height, and general status. He was currently on intravenous hyperalimentation, but was being urged to take food by mouth. The physical therapist reported that when Alan had first come to the hospital he had been walking, but he only did so now with a great deal of encouragement. It was her opinion that the reluctance to walk had a psychological basis. The mother expressed her agreement with this. The child life worker had found it difficult to engage Alan in play activities, although he would occasionally play a game with her. The school teacher reported that Alan complained about going to school, saying he could not see, could not use his arm and had difficulty speaking. The teacher therefore recommended shorter sessions for him. The rabbi was seeing the family regularly and reported that they were in need of all the support staff could give.

The family's discussion focused largely on treatment issues and the possibilities for Alan. At the time of tumor recurrence, Alan began to express discouragement about the usefulness of further treatment, although the parents were firm in their desire for continuing. This issue was discussed with Alan and his parents during the conference. How much the child understood the various alternatives was unclear, and so the treatment options were again presented at his level of understanding. The parents questioned whether a child of Alan's age could and should have the right to make a decision about treatment. The physician explained that Alan could not tolerate MTX again and the likelihood of a response to the other

available treatments, such as Dis-Platinum and nitrosourea, were small. The question of whether to continue treatment was one which the family would have to decide, based on their willingness to tolerate the side effects and risks involved at this time.

The staffing conference in this case was used to acquaint Alan and his family with the options open to them and to provide an opportunity for them to inform us of their preferences. It was also an opportunity to discuss subjects that Alan may have wondered about (e.g., the seriousness of his situation) but which were difficult for his parents to face. It appeared that Alan was considering the possibility of discontinuing treatment for the tumor (which would have been acceptable to the staff), but he also indicated that he did not want the decision to be his alone. His parents, especially Mr. S., clearly indicated their wish to consider additional chemotherapy. Recommendations from this conference included: 1) Further consideration and deliberation about whether to proceed with treatment. The physician and Mental Health Division staff were available to assist the family in their decision-making. 2) Concentrated efforts to help Alan go home for a short time. The physician recommended hospitalization for 10 days or discharge sooner if Alan consumed 2000 calories per day by mouth. 3) Continuance of individual and family psychotherapy.

During the days following the staffing conference, Alan's mood improved considerably and he became much more active. The parents indicated their desire to take him home for a pass over the weekend to see how he would do. He was given a 24-hour pass which went very well, and on the following Monday he was discharged to spend some time at home.

Subsequently, Alan chose to undergo two intraarterial Cisplatinum treatments. These have been effective, and two months from the staffing conference, Alan is at home with his family.

Results of the staffing conference. There are two purposes of the staffing conference: First, it provides a place for multidisciplinary sharing of information and the integration of those data into a rational, individualized treatment plan. Meeting together and discussing these is reassuring to the patient and family and is a concrete gesture of support. The first purpose is, therefore, of direct benefit to the family. The second purpose is for instruction of the staff about areas outside their immediate field and for sharing personal reactions to particular situations and events. In addition to these, the conference also provides an opportunity for staff to obtain feedback on how the families view us.

The positive effects of presenting the family with well organized reports of their child from a number of perspectives

should not be underestimated. Simply presenting these data all at once often provokes questions from the parents that had not been consciously formulated up to that point. For example, one mother began to come to terms with her degree of commitment to her child and to treatment only after receiving full reports on the status of health and the threats of the disease to her daughter--all of which had been prompted by her insistence on a pass from the hospital.

The staffing conference serves also as a model to staff and families for open communication about the disease and about emotional matters. By observing psychological interviews, staff learns how to obtain information and convey recommendations in a manner which is tolerable to the family and which will not provoke defensive responses. Parents too may see that children can be talked to very much like adults and that they understand far more than adults expect. One child said to his father after the conference, "I know why mother was crying, she worries that I might die." With this statement, the mother could see that such a discussion was not threatening to the child; quite the opposite, he showed renewed spirit to do what he could to help himself get better. Most families are noticeably more at ease with staff after the conference. Diminution of depression and suspiciousness are frequently noted among all family members immediately after the conference and this continues over time.

Another psychological effect of the staffing conference is an implied or sometimes explicit statement of support by a large group of concerned staff members. This has had significant impact in reducing anxieties, doubts, and suspicions about treatment and the staff's intentions.

There are benefits to staff as well, related to openly expressing opinions and attitudes; but, in addition, presentation requires some degree of forethought and organization of their material on a particular patient. In the course of formulating these reports, new perspectives and perceptions may arise that might not otherwise surface.

A number of recurrent issues have become recognized. Even though the cases are often selected because of perceived problems, the salient issues become apparent during the course of the meeting itself. A list of issues most frequently addressed:

1. Language barriers. Sometimes the conference is done with translation. Nine families have been staffed with the issue of language barrier paramount. It has been made abundantly clear how much these families miss in terms of information.

2. Medical uncertainties or threatening intervention. Bone marrow transplants, difficulties in determining diagnoses, psycho-

somatic tendencies, amputations or other surgical procedures, the gravity of a patient's medical condition, genetic factors, malnutrition, or inordinate pain are examples of concerns under this heading.

3. Management issues. Management of the troublesome patient or parent, families with multiple problems--medical, financial, psychosocial, hospital operations and rules, preparation of a family who has decided to take the child home for the last time.

4. Family issues. The effects of the disease and treatment are always addressed: discomfort, disfigurement, family upheaval, increased focus on the patient-child. In addition, sometimes the "good" patient and family are reviewed. New patients are introduced to the concept of maintaining normalcy. Patient/families who detest the hospital are helped to integrate it better into their lives. Family issues include concerns of patients and parents. Patient's behavior generates recurrent issues: resistance to treatment, immaturity, behavior problems, eating problems, drug addiction or the prevention thereof, depression, withdrawal, school refusal, handicaps (blindness, deafness, mental retardation).

For parents, the following issues may arise: emotional susceptibility or breakdown, authority/control issues, pathologic or maladaptive denial, marital estrangement, parental dominance, absent or distant parents, very young parents, hostility, suspiciousness, and ineffective parenting skills.

The effect of staffing as a demonstration project on the care system. Ideally, a staffing conference should be set up for every patient on admission, after completion of the initial work-up and at yearly intervals or whenever a significant turn in the clinical course occurs, whichever comes earlier. Clearly that is beyond our capabilities. Therefore, the staffing conference has to remain a model, and a lever in the continually rising awareness towards one goal of total care. The staffing conference clearly succeeds in that.

First of all, the conference is more than a design of an individualized treatment program. There is an acute awareness of the true participation of the family in their own care. All issues surrounding informed consents and other knowledgeable participation are continually clarified.

There is more mutual respect for the role of the individual professional. Each presents his or her specialty and recommendations. Each approaches the patient with specific expertise. The best illustration is given by the chaplain who explains the religious affiliation, if any, the meaning to the family of their faith and understanding, and his recommendation regarding the implications for care and support.

There is no doubt that the heightened awareness of equal participation of patient and parents and all professionals has generated a more acute awareness of the moral and ethical dilemmas posed by care by research. The issues are more clearly posed: the problem of difficulty in reconciling the need for research with the ethical prohibition against conducting research on captive subjects is recognized (van Eys, 1978). However, precisely because of the patient participation, the patients are, indeed, seen as persons and are allowed a true consent, informed by us but allowed to process that information towards a consent or refusal as they see fit (Holt, 1978).

IV. CONCLUDING REMARKS

The staffing conference is indeed the medical equivalent of the ARD-IEP of the educational community. However, it is also vastly more. There is true integration of the family into the therapeutic community as coequal partners. This has a major impact on the patient. Quite frequently we see an immediate change for the better in very anxious or troubled patients. Testimony to this was given by one child who, immediately after the meeting said to his parents, "Let's have another one of those." His behavior, which had been rebellious and oppositional, took a distinct change for the better. The conference has an equal effect on the staff who feel pulled into the community towards a common goal. This is different from a team in the usual perception of that approach. As stated elsewhere:

> There is a tension, an antinmony, between the community decision and the individual, between the rule and the case. The child who enters must be helped, but the community must have a starting point from which to begin adjusting to the individual. On the physical side of oncological medicine we start with a beginning dose of a chemotherapeutic agent and adjust from there to tolerance. The mental health side is no different. There is a desired endpoint and one adjusts to individual needs (van Eys, 1981).

The usual team is the starting point. The staffing conference allows adjustment to individual needs.

Finally, the staffing conference is sensitive to changing realities in cancer management. A preconceived team concept of support may be relatively resistant to simplification of cancer management. We must, in fact, remain prepared for cure rather than for the almost cure of a persistently captive patient.

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NOT EVERYONE IS READY TO BRING IT UP IN THE CLASSROOM: DISCUSSION OF DR. VAN EYS' PAPER

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Van Eys and Copeland have discussed their approach to systematic involvement of pediatric cancer patients and their families in the treatment planning process. They describe a formal group meeting using therapeutic community concepts in which patients and their family members are invited to participate. This approach is reported as successful by the authors and suggestion is made that given greater resources, more frequent utilization of the process could be made. Any attempt to improve communication with patients and their families is laudable. Even more so is a sincere effort to involve patients and families in the treatment planning process in a meaningful way.

RATIONALE

Rationale for the approach is focused on the rights of handicapped children. The rationale would be greatly strengthened if it focused on the rights of all children. It might also identify appropriate legal, ethical, and practical issues. Parents exercise the derivative constitutional rights of their minor child to self-determination, privacy, informed consent and bodily function. Courts have authorized medical care over parental objection only when the life of the child weighed in the balance (Monaco, 1980, 1981).

Consent of a parent or guardian is valid for established and generally accepted therapeutic procedures performed on a child. Parental or guardian consent generally has been accepted as adequate for therapeutic research, although this issue has not been completely resolved in the courts. When research might expose a

subject to risk without defined therapeutic benefit or other positive effect on the subject's well-being, parental or guardian consent appears to be insufficient (NIH 1973, 1974).

Dyck and Richardson (1979, p. 245) write that among societies most inviolable structural and values are the requirements for informed consent which protect veracity or relationships characterized by promise-keeping and truth-telling; freedom or a person's general right to pursue his own happiness and to decide what risks to his own body and his own welfare he will take; and justice or the distribution of goods in accord with a standard of equity and to redress for undeserved harm. These are values people will die to preserve, values without which social systems and interpersonal relations break down and cannot function.

Pragmatically speaking, it is not practical and rarely feasible to treat a child in today's world of complex cancer therapies and research questions without the optimum cooperation of the child's parent(s) and family. Clients of today's health care system no longer place blind trust in care givers. On the contrary, they are confronted if not besieged with varied alternatives, conflicting opinions, and unanswerable questions. In order for the parents' cooperation to be utilized optimally, they must understand the nature of the problem, the resources available to treat the problem, and the plan for doing so. Issues of continuity and compliance cannot be addressed satisfactorily without the full support of all.

If a major objective of the staffing conference is to communicate with the patient, family and members of the health team, and to facilitate their involvement and support, then these legal, ethical and practical issues provide a very good rationale for the approach.

COMMUNICATION

The authors suggest that some concepts in the therapeutic community process might appropriately be applied to this model, e.g., in a therapeutic community, emphasis is placed on socialization and group interaction. The focus is on communication as an opportunity for living and learning. All aspects of the clients' lives are seen as presenting opportunities for learning and growth (Jones, 1953). Principles of therapeutic community application might arouse questions regarding the exclusion of a major section of the patient's hospital community, i.e., other patients and their families. Therapeutic community concepts can be effectively applied to family or patient groups where there are shared experiences, concerns, problems and resources. The experiences, contributions, ideas, suggestions and questions of other patients and their families are missing in the staffing conference.

An analogy might be made between the staffing conference and a team "huddle" in which the patients and family have been invited to participate. Frequency and timing would be important when attempting to evaluate the contribution of the staffing conference to the communication process.

Refusals to participate in the staffing conference are reported as minimal (five refusals out of 96 or 5.5%). What alternative sources of communication, information and support were offered to participants? Is the choice between communication in a group setting and poor, inadequate, or distorted communication? It would be interesting and helpful to know typical patient/family preference for alternative methods of communication.

The staffing conference has some obvious benefits for staff members and thus is potentially beneficial for patients and families. However, the introduction of a group model will definitely impact the communication process, group behavior norms, values and goals will change with each group meeting. The impact of group interaction on the communication process needs further exploration and discussion.

COST

The cost associated with the model is not discussed. A cost-benefit analysis of this approach would be most useful in determining its feasibility in other settings. If the patient/family were required to address the true cost of a staff meeting, one can imagine the selectivity involved in choosing what on the surface must appear to be an expensive option.

EVALUATION

Objective systematic evaluation of the approach is not reported. Study of the effectiveness of the model is limited to intuitive analysis of participant observation and anecdotal reporting. A setting where other methods of patient/family communication and involvement are utilized is fertile ground for comparative analysis. Questions such as: What types of patients and families learn and benefit most from this model? What kind of information is assimilated best using this method? How is sensitive or painful information communicated using this model? What are the advantages and disadvantages of the model? Could all be addressed using a systematic evaluation of the program? In order for this approach to be put forth as a model for replication, these questions should be addressed.

SOCIALIZATION OF THE PEDIATRIC CANCER PATIENT

Attempts to improve socialization of the pediatric cancer patient led by Dr. van Eys and others have called attention to many deficiencies in the typical cancer center environment. I believe all would now agree that the pediatric cancer patient should be socialized in an environment that is as normal as possible.

The staffing conference in Pediatric Oncology is a potentially viable option for effective communication. Use of this option must always provide for a sensitivity to and awareness of the psychosocial needs and strengths of the patient and family members. In the book The Truly Cured Child, Dr. van Eys writes (1979, p. 96), "Normal child development suggests that the child made the right choices in his growing process. We must supply a healthy selection of options to allow a choice (emphasis mine). Communication options might include a quiet whisper or a general class discussion. Just as some important messages would never be heard if only whispered, not everyone is ready to 'bring it up in class'".

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THERAPEUTIC STRATEGIES AT PSYCHOSOCIAL CRISIS POINTS IN THE TREATMENT OF CHILDHOOD CANCER

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INTRODUCTION

How can we best deploy the usually scarce mental health resources to provide optimal psychosocial support to the pediatric cancer patients and their families? This is a persistent question that is asked of us by social workers from other centers, and that we ourselves must grapple with at Memorial. We are currently defining ways of tracking the illness and its treatment, including psychosocial interventions, in order to determine those points of social and emotional stress at which patients and families require special help to enhance optimal coping.

In a previous paper, nine of these crisis points were described (Christ, 1982). These were identified through our clinical experience and research as points during which patients and families confront special stresses. Koocher and O'Malley (1981) described many similarities with these nine crisis points in their data from long term survivors.

In this presentation, we would like to expand the information generated about eight of these crisis points in two areas through:

(1) the development of a framework for deployment of staff in relation to the patient and/or family's degree of social and emotional vulnerability and;
(2) the identification of specific interventions and techniques at each of the identified stress points.

PSYCHOPATHOLOGICAL CONTINUUM

The interventions and techniques used with different patients and families are similar in relation to the nature of the stress, but differ in frequency, intensity, and kind, depending on whether the patient and/or family are psychologically normal, vulnerable, or psychopathological. We have found it helpful to divide families into three categories of psychosocial vulnerability: (1) those with previous or current severe psychopathology (about 5% at Memorial Sloan-Kettering Cancer Center); (2) those with some degree of social or psychological vulnerability (over 50%), and; (3) those considered normal.

The normal or even vulnerable patient responds much more rapidly to fewer interventions, and demonstrates a capacity to assimilate and generalize insights gained through these interventions to other situations or stress points in the illness (Christ, 1982). This is in marked contrast to the pace of change relative to the number of interventions in the psychopathological cancer patient. Many years of experience working in psychiatric clinics and in mental hospitals gave me a perspective on the profound distinction in the response of the severely stressed normal, even vulnerable, and the response of the psychopathological to a very few sessions.

SEVERE PSYCHOPATHOLOGY

A. Psychosis

The patient or family member with a history of psychotic psychopathology prior to the cancer diagnosis should be identified during the initial evaluation process. Professionals in a medical setting are reluctant to inquire about previous psychiatric hospitalization or counselling. However, it can and must be done in a routine and matter of fact way. It is more likely that severe psychopathology will be overlooked in the parents or siblings rather than in the patient.

Why is this early identification necessary? The psychotic patient or family member is prone to misinterpret information and to respond in stereotyped, idiosyncratic, less flexible ways to stressful situations. If treatment for their psychotic condition is not current, they might need to be encouraged to resume contact with their previous therapist. With the patient or family member who has had psychotic episodes in the past and may now be in remission, the staff should be prepared for the possibility of a recurrence of this behavior under stress. A clear plan of how they should respond should be generated, and should include such factors as identifying responsible family members to contact, knowing where the person could be committed if necessary, who would take responsi-

bility for this procedure, etc. In general, this patient or family member, requires more active structuring of his experience throughout the medical treatment, more direction and prescription. While his psychiatric illness may be exacerbated by the stress points in the illness, psychosocial treatment by the hospital mental health team should be directed toward his response to the fact of a potentially fatal illness and the changes in life style demanded by it.

While severely pathological patients or family members may experience exacerbation or relapse of their psychiatric disease under these stresses, more attention needs to be given to their psychological illness than to the particular stress points of cancer. In our experience, the psychotic individual more often responds to idiosyncratic pressures and stresses, and may cope surprisingly well with the more "real" crises. As a consequence, the monitoring of this individual by the mental health team needs to be different than it is for the normal or vulnerable individual.

B. Personality Disorder

Of greater concern than the psychotic, because of the difficulty in identification, is the patient or family member with less flagrant psychopathology, such as individuals with borderline character organization (Kernberg, 1975). These difficulties may not be immediately apparent, but may be manifest in a variety of destructive behaviors, e.g., alcoholism, depressive neglect, or increased interpersonal conflicts with staff as a result of the propensity for splitting staff into "good and bad." These patients or family members' overt responses of anxiety and depression to the stress points of the cancer course may have equal emotional intensity to that of the more normal families; however, their underlying character structure renders them less resilient and less able to deal effectively with certain situations. For example, they may not be able to set limits on regressive behaviors in the ill child, or may use splitting defenses, dividing staff into good and bad, thus creating excessive tension in the ward staff. The usual exploratory techniques, encouragement of abreaction, and ventilation may inadvertently foster symbiotic dependency rather than relieving anxiety and encouraging growth.

A fifteen year old leukemia patient from another cancer center was videotaped over the five year course of her illness. The mother worked as a patient advocate on the pediatrics unit throughout her daughter's treatment, attacking what she perceived to be deficiencies in the delivery of services to patients. The mother had problems in her personal life, which included an overt hatred of her own mother, increasing conflict with her husband whom she divorced during this period. She refused psychotherapy away from

the cancer center for these acknowledged personal problems, and chose instead to obtain occasional counselling sessions with her daughter's therapist, a psychologist at that center. This mother remarried a few weeks prior to her daughter's death, and acted out her unconscious conflicts in other ways, such as actively encouraging her daughter to die. The therapist showed the tape, which included a scene with the mother and her friends digging the patient's grave. The mother was unable to resolve her pathological involvement with the patient or the cancer center. It seemed clear that this mother was symbiotically involved with her daughter, and the therapist had unwittingly fostered her dependent over-involvement with the institution as well. Classic borderline pathology was not recognized. Rather than setting limits, structuring her behavior, and reducing her excessive involvement with the institution, the staff inadvertently fostered her pathological regression to a more symbiotic level. Either Kernberg's (1975) focus on identity diffusion or Masterson's (1972) focus on symbiotic dependence as central to borderline pathology can be used as diagnostic guidelines for these patients and family members and appropriate structuring techniques can then be utilized to enhance adaptation.

In summary, we have highlighted the following issues with the patient or family member with more severe psychopathology: (1) the reluctance of professionals to inquire about prior psychiatric illness in the initial evaluation; (2) the ease of misdiagnosis, especially of borderline conditions; (3) the need to develop clear ways to handle potential crises such as psychotic deterioration; and, (4) the need to focus on their holistic and idiosyncratic responses to the cancer diagnosis and its consequence.

VULNERABLE

The vulnerable patient or family member can be identified by a number of characteristics described in the literature (Kaplan, Smith, Grobstein, and Fishman, 1973; Koocher and O'Mally, 1981) as being associated with poor adjustment outcomes and adaptational failures. These include staff-patient dissynchrony, closed communication patterns within the family, single parent families, low socioeconomic status, and nonsupportive marital relationships. In addition, we have identified six other characteristics in the vulnerable families. These characteristics include: (1) Patients or family members who have had greater than expected difficulty with individuation-separation, some of whom may have suffered early deaths or losses or who have experienced deaths from cancer in the family and may find it difficult to maintain a hopeful and realistic perspective. (2) Patients who are more action prone may find careful attention to the details of treatment difficult. (3) Patients or family members who are somewhat mistrustful (i.e., paranoid) of medical staff are prone to problems in adaptation. (4) Intellect-

ually limited patients and families are vulnerable, as are patients who have academically and socially achieved only with great effort, and for whom falling behind due to treatment may present a severe discouragement and an overwhelming loss in self esteem. (5) Patients who have other physical or mental handicaps prior to the diagnosis of cancer are also more prone to have difficulties in coping with yet another problem that sets them apart from peers. These family members are often overwhelmed with the unfairness of their plight. (6) The presence of other serious illnesses in the family, especially another sibling with cancer or other chronic illnesses, or a spouse with chronic illness, can create special problems for families.

The overt emotional responses of the normal and vulnerable patient and family to the stresses of cancer may be identical, but the vulnerable family needs more active monitoring to avoid coping failures and the development of chronic maladaptive patterns (Chodoff, Friedman and Hamburg, 1964; Futterman and Hoffman, 1978; Kaplan et al., 1973).

Mary is a 14 year old female patient diagnosed with osteogenic sarcoma at the age of 11. She currently has no evidence of disease. She had bone replacement surgery on her leg, which was then followed by a year of chemotherapy. A social work student followed Mary during the first year. Both mother and daughter state that the student was very helpful to them during this period of intensive treatment spanning the first four stress points that will shortly be described. Mary had tutors during her year of treatment, but she had difficulty keeping up with her assignments due to the pain, discomfort, and interruption of regular tutoring on account of the treatment. When she returned to school, she found herself academically far behind, "I didn't know what they were talking about anymore. I was a good student before, but it was very different now." She gradually drifted to a crowd of students who did not spend time on school work or sports. "I used to be a great runner--ahead of everyone" said Mary, "but now they all run past me--I'm the last one."

I interviewed Mary's mother, who confirmed that Mary had few areas of school-related mastery left, except that she did maintain a good social life. Mrs. M described gradual deterioration in the family's socioeconomic condition since the termination of treatment and the family's contact with the social work student. Mr. M increased his drinking after Mary returned home, and because of this, lost a job he had maintained for 15 years. He consequently lost his medical insurance. Mrs. M went on welfare in order to obtain Medicaid, even though she felt quite stigmatized by this in her middle-class community, and personally felt this as a significant loss of self esteem. Mr. M is still unemployed. Mrs. M has gained 30 pounds.

This is an example of a patient and family who reasonably mastered the stresses of the initial diagnostic and treatment phases of cancer, but were unable to cope with Mary's re-entry into school and community, and the termination of her treatment with all of the uncertainties inherent in that phase. Areas of potential success, e.g., school work, were in part also undermined by her school's inability to respond to her special situation and provide needed additional supports. The family has emerged from this phase weakened and less able to cope with any future stress. Without intervention, one could not be optimistic about Mary's future development as a contributing member of society. As she described the course of her illness, she appeared significantly depressed, had low self esteem, and was preoccupied with containing her anger. Although she blamed the illness for these feelings, it is quite probable that a very significant factor was her maladaption to school re-entry.

In general, there is a tendency in a medical setting to under-identify these vulnerabilities in patients and families, and not to appreciate how active psychosocial intervention can prevent the development of maladaptive processes.

NORMAL

In contrast to the pathological and vulnerable families, the normal or super-normal families can best be characterized as: (1) able to cope by using all available resources within and outside the hospital, (2) they tend to have many more people available to them, (3) more social and economic resources, and (4) maintain open communication patterns within the family and with the hospital staff. Where mental health resources are limited, these families are usually not monitored. Following a comprehensive orientation to available services, one tends to rely on them to initiate and use professional help appropriately. Generally they seek out mental health staff at points of severe stress. The staff, on the other hand, find these patients and families extremely gratifying to work with, because they clearly identify their needs, they respond rapidly to psycho-social interventions, and they are appreciative of staff's knowledge and skill.

Because of overwhelming needs with vulnerable and pathological families, one is left with an uneasy feeling that these normal patients and families may be underserved. In a recent follow-up survey, one mother wrote "We coped, but things may have been more tolerable with added help."

During the past decade, mental health professionals (Binger, Ablin, Feurstein, Kushnor, Zoger, and Mikkelson, 1969; Friedman, Chodoff, Mason, and Hamburg, 1963; Knapp and Hansen, 1973) have emphasized helping the cancer patients and their families cope with the

diagnostic and the dying process. In our experience, diagnosis and death are but two of a number of crisis points during the course of illness and treatment. Each phase, if managed well, can result in personal growth of both patient and family, and a greater resilience for mastering subsequent phases. Conversely, the inability of patient and family to cope well with any given phase may result in diminished capacity to meet future phases, resulting in a gradual deterioration of psychosocial functioning of patient and family.

PSYCHOSOCIAL CRISIS POINTS IN CHILDHOOD CANCER AND ITS TREATMENT

We have identified the following eight crisis points in the course of cancer and its treatment which represent stress points for patients and families: (1) the diagnostic process, (2) the onset of treatment, (3) negative physical reactions to treatment and treatment side effects, (4) termination of a treatment protocol, (5) reentry into school, social and family life, (6) recurrence or metastasis of the disease, (7) initiation of research treatment, and (8) termination of active treatment and terminal illness. Let us briefly examine each of these.

I. Diagnosis

The mental health professional has four tasks during the diagnostic phase: (1) gathering basic information leading to an overall assessment of strengths, vulnerabilities, and/or degree of psychopathology in patient and family, (2) facilitating the family's processing of information and helping them cope with the emotional impact of the diagnosis, (3) specific assessment of their response to the diagnostic stage, and (4) assisting the family in beginning to reorganize their lives to meet the demands of treatment by helping them solve the many practical problems created by their child's illness.

Formal information-gathering may have to wait until the family assimilates the initial emotional shock caused by being informed about the diagnosis. However, it must occur during the course of the diagnostic process both directly through frank questioning and indirectly as the worker observes the family's method of coping with their distress. The indirect observations of the response to the illness are especially helpful in determining such psychological reactions as a narcissistic injury; evidencing problems with anger, suspicion or mistrust of medical judgments; use of splitting defenses as evidenced by excessively criticizing some staff and aggrandizing others; excessive self blame with consequent high levels of guilt and depression; detachment from feelings about the illness; isolation of affect; or withdrawal and passivity. Responses such as these often predict responses to future crises

because they are usually manifestations of a pervasive characterological style. Observations of interpersonal interactive patterns are especially important and include: Are spouses openly supportive of each other or do they blame each other and withdraw support? How do they share information and feelings between family members? Such observations are invaluable in diagnosing family patterns, such as pathological closed communications systems as described by Minuchin (1965).

The worker also supports the family perceiving the child no longer as healthy, but as ill, and the concomitant profound alterations this will make in their lives. At this point it is imperative that once past the initial shock, the family move from a fear of death to a life focus. A useful technique for facilitating this movement is to enlist the family and the patient's help in predicting how they will cope, identifying strengths as well as areas with which they may need help, and inquiring how this help may best be provided by the hospital staff. This exploration gives permission for, and models a self monitoring process.

In summary, indication that the family is coping well during this stage include that by the end of the first week following diagnosis the patient and family should be able to deal more realistically with information, and be well into the process of planning, altering, and making realistic modifications in their lives to begin to prepare for the next stage, the stage of treatment. The family now perceives their child as ill, but as one requiring treatment. Also, the family that copes effectively is now evaluating and altering non-illness related plans that may be affected by the illness.

II. Induction of Treatment

Beginning treatment should be accompanied by a lift in mood in patient and family members, even though treatment may be rigorous. They are now actively engaged in attempting to control the disease, and therefore begin to feel an overall increased sense of control. For most pediatric cancers, the most rigorous phase of treatment, the induction, will last from three to four months. If all goes well, the whole protocol will be completed after approximately three years. Patients with osteogenic sarcoma have a more rigorous treatment throughout the first 12-18 months of that protocol, often involving surgery.

Primary psychosocial interventions at this induction treatment phase include: (1) clarifying information about treatment and its demands, (2) offering practical assistance to families in order to meet the demands on their emotional, social, and economic resources, (3) helping families to motivate the patient to become an active participant in his treatment and overcome any resistance or problem,

and (4) encouraging families to integrate the patient and his treatment into normal family living patterns, with appropriate attention to the needs of all family members including the siblings.

Patients and family members who actively question the various aspects of the treatment and demonstrate an ability to follow through on information obtained are in general adapting well. Their questioning demonstrates acceptance of the task and of their role as active participants. It is especially important for teenagers to become active in managing aspects of the treatment, such as, for example, testing their own urine at home and monitoring their fluid intake. Questioning by the latency age child and adolescent can be an indication that good defenses, such as intellectualization, are being mobilized, and should be encouraged by giving appropriate, even technical, information. Patients and families who adapt well during this phase are also able to moderate their affect. Although they may at times be anxious or depressed, they are also able to feel well when the patient is not in physical distress. Gradually, over several months, they redefine "normal" for themselves and their family, and the patient's treatment and his reactions to it are integrated into ongoing family life.

Patients and families who are having difficulty during this phase may (1) ask the same questions repeatedly, (2) demonstrate an inability to follow through on instructions, (3) maintain a distressed mood even when the patient's immediate physical condition does not warrant this level of concern, (4) be excessively passive, not asking questions, or appearing unconcerned about the details of the treatment, or (5) experience unusual difficulty solving practical problems such as finding transportation to and from clinic, caring for dependents, arranging finances, or keeping clinic appointments.

Mrs. M remained quite depressed following her 15 year old son's surgery. She cried during clinic visits, acting as though her son was terminally ill rather than responding well to treatment as he in fact was. She also seemed unable to organize transportation to clinic, although she had many personal and social resources and in the past had been quite successful in using them. When the worker inquired about her persistent depression, Mrs. M revealed guilt about her ambivalent feelings at the time of the patient's birth which had led to a postpartum depression. She feared her negative feelings at his birth had caused his illness. It was pointed out to her how well she had cared for her son in spite of her feelings, as evidenced by his successes in social and academic life, and it was emphasized that it is quite normal to have mixed emotions about one's fourth child. In addition, Mrs. M was directed to her local physician who had treated her in the past with medication for depressive episodes. As a result of these interventions, her mood

improved, she organized her transportation and supported her son through a successful course of treatment. Mrs. M's persistent depressive mood and difficulty in organization were used as indications of adaptive failure at this point.

Specific psychosocial interventions during the induction of treatment should include, in addition to medical and nursing educational programs, (1) play therapy groups to clarify younger childrens' fantasies and misinterpretations about the disease and its treatment, (2) individual play therapy with children and their parents to facilitate communication, (3) an adolescent group which usually enhances a more active role and (4) use of adolescents further along in treatment to encourage those patients at the induction of treatment stage.

In summary, there are two indications that a family is doing well during this induction of treatment stage, (1) a lifting of mood and a moderation of affect, and (2) active participation in treatment, and the use of healthy defenses such as intellectualization, especially in latency and adolescent youngsters.

III. Negative Physical Reactions to Treatment

The third crisis point occurs at the time of negative physical reactions to treatment such as toxicity, infections, or hair loss. If the patient presents with toxicity or infections, the mental health worker, along with the rest of the medical team must assess whether this is the result of inadequate care at home. If the care was inadequate, additional education is provided, along with such practical assistance as arrangement for a visiting nurse. In addition, the mental health worker assesses emotional factors that may have adversely affected treatment compliance.

Jill is a 13 year old with mild cerebral palsy, newly diagnosed with osteogenic sarcoma. She is the favorite child of an alcoholic father and an intellectually limited, depressed mother. Jill received the first two courses of high dose methotrexate in the hospital. Nursing staff was in charge of her care, and she experienced only minimal side effects. Her mother was then very carefully taught how to do mouth care, give the medication, and manage fluid intake and output, all of which she accomplished well. After being discharged and receiving her next medication course in the clinic, Jill was readmitted with toxicity--painful mouth and esophogeal sores, low blood count, and fever. Exploration revealed that, like many 13 year olds, Jill had rebelled and would not cooperate with her mother's care. The toxicity resulted from her noncompliance with mouth care and fluid management. The mother, in part because of her depression, was unable to set firm limits and insist on these procedures. After confronting Jill with the facts,

staff acknowledged her need for greater control. She was given appropriate responsibilities for her care, which she appreciated. The mother's depression and feelings of being helplessly overwhelmed are being addressed in ongoing counselling. The visiting nurse service was arranged to provide reinforcement of the regimen at home. Jill was discharged again, and at this point (two months later), is doing well.

Even if care at home is adequate, all parents often need reassurance around feelings of guilt that result from a vague feeling they are doing something wrong. Both patient and family need help in keeping a perspective on the positive effect of treatment despite the painful side effects. In a survey of adolescents with a variety of chronic illnesses, Kellerman (1980) found that the cancer patients viewed the treatment as worse than the illness because of the major impact it had on normal life activities. An indication that the adolescent is positively engaged in coping with these side effects is their active experimentation with ways in controlling their reactions during the period of the most severe side effects.

The almost universal hair loss is always depressing to patients when it actually begins to occur. Anticipatory discussions between patient and parent should be encouraged, emphasizing that the parents need to allow the patient to control how the exigencies are managed, e.g., whether she will wear a wig, a scarf, or nothing. Anticipatory discussion with the patient around interactions with family, friends, and school can also be helpful. With latency aged children and adolescents, some discussions with patients who have already managed this phase is often useful.

The characteristics of vulnerable families that are particularly relevant to this state are low socioeconomic status, families with languages different from hospital staff, children with repeated school failures, and children who are rebellious or negativisitic.

Indicators of successful coping with negative reactions to treatment include: (1) adolescents developing ways of having some control over side effects; (2) children talking or playing out thoughts and feelings about the side effects; (3) family emotional reactions being temporary reactions to the situation rather than pervasive moods; and, (4) family and patient maintaining long range perspectives on the importance of treatment, even in the face of severe side effects.

IV. Treatment Termination

Coming off of treatment is the fourth crisis point, whose psychological significance to patients and families can easily be underestimated. The long term survivor families (Koocher, 1981) remember this as a time of special stress. There is relief that

treatment is finished, but also a fear of being without it and concomitantly of losing the support of the professional staff. For all families, a review of the course of treatment with special emphasis on the natural feeling of ambivalence around leaving careful monitoring by professionals is essential. A denial of the families' dependence on the institution often leaves even normal families with a sense of puzzlement about their feelings. During this review, the family's successes in coping with previous stress points should be affirmed, but now with a focus on goals for the future, anticipated problems and ways of coping with them.

Jennifer is a 14 year old patient with osteogenic sarcoma who had bone replacement surgery. As she successfully finished the treatment protocol, she began to discuss with the social worker her thoughts about possibly wanting an amputation in the future, because it would give her more mobility than the current bone replacement. She was clearly looking toward the future, and at alternatives of how she may be best able to solve some of the long range problems her illness presented.

Patients and families most vulnerable to difficulty with this phase are those who are: (1) excessively authority dependent, (2) or excessively compliant. Families who have had special problems with separation-individuation or who have inadequate social supports tend to be excessively dependent or compliant.

Indicators that patients and families are managing this termination phase well are their beginning to engage in long range planning. The parents shift to a greater involvement in aspects of their own lives. One highly critical dilemma for patients, families, and staff, is determining when a family's focus on the reality principle, i.e., short term goals and planning, is more appropriate. When should the patient be pushed to confront the immediate anxiety cause by moving fully into academic and social activities for the sake of a better long term adjustment? And, when should he be allowed to avoid those emotionally painful experiences? Clearly, the successfully adapting family at the end of a treatment protocol will be resolving this dilemma in the direction of the reality principle, i.e., actively planning for the patient to take on responsibilities more commensurate with his level of development.

V. Reentry into Normal Living and its Concomitant Stresses

The preparation for reentry into normal school, social and family life should already be completed by the time of termination of the treatment protocol. The reentry process occurs not once, but each time an exacerbation responds to treatment, and a new remission period occurs. The sooner the patient returns to a normal school and family environment after the induction of treatment, the

better will be his long term psychosocial adjustment (Deasy-Spinetta, 1981; Kagen-Goodheart, 1977; Koocher and O'Malley, 1981). We have also found that the adolescents with visible physical disfigurements and impairments are especially vulnerable during this crisis point (Kagen-Goodheart, 1977; Plumb and Holland, 1974). They may use home instruction longer than is justified by the physical limitations because they fear such things as rejection by peers, confronting academic losses, etc. We understand this in part as a difficulty in overcoming the regressive pull of the noncompetitive home environment. Patients must again adjust to the discipline of studying, being responsible for assignments and following structured daily routines. If the patient gives in to this regression, it also affects siblings, who may both envy and resent what they view as unfair indulgence of the patient and excessive demands on themselves. Thus excessive conflict with siblings is often an indicator of the patient's excessive regression.

The parents' reluctance to insist on the patient's return to school usually reflects an underlying pessimism, an inability to be hopeful in facing the future. Stated another way, an excessive focus on the pleasure principle rather than the reality principle reflects a conscious or unconscious erroneous expectation of the child's more imminent death. It is as if the parent were saying: Let him get maximal pleasure from his remaining months. The patient's normal psychosocial development is retarded by this isolation, and eventually results in depression, both in the patient and his family.

Other characteristics that render patients vulnerable during this phase include: (1) low socioeconomic status, which often means less accommodating schools for the handicapped, (2) personality characteristics of passivity, (3) propensities toward phobic withdrawal, (4) cultural difference with school personnel because this often results in poorer communication, and (5) closed communication patterns within the family which limit the family's ability to resolve conflictual feelings.

A broad range of interventions are needed to resolve problems arising at this crisis point. These include interventions not only with patient, parents and siblings, but also often with school personnel and other community agencies. This problem is so ubiquitous that a number of cancer treatment centers are developing regular educational programs for the school personnel who teach the patients (Ross and Searvalone, 1982). In addition, special counselling techniques may need to be utilized for certain problems. So, for example, girls with disfigurement secondary to the disease or its treatment require counselling geared to the establishment of a reasonable self image, encouragement to take risks in social situations including dating, dealing with excessively adverse parental and/or sibling reactions to the disfigurement, etc. Such

specialized techniques as task prescription (Berlin, 1982), i.e., "This week you are going to walk up to a boy you don't know well in school and are going to initiate a conversation" should be tried.

Maria is a 17 year old patient diagnosed with osteogenic sarcoma at age 14. Living in a lower class Brooklyn neighborhood, she has remained out of school now for the past three years. She observes "They are teaching patients so much more now than when I was first diagnosed. Today, I learn a lot about cancer from T.V. Now they also have those groups on the floor so people are talking more to each other. I didn't really know what was happening to me for a long time." Although there are many reasons for her failure to return to school, certainly the lack of continuous information and support played a significant role in her adaptational problems. Maria did not get through stage five: reentry into school. Her mother, a single parent, was reluctant to pressure Maria to return to school. Instead, she focused primarily on the present and on avoiding the uncertainties of the future. Maria had a history of phobic reactions to stress, a fact which should have been used to predict that she would have difficulty at this stage. In addition, she was culturally different from the majority of the hospital health care team, a fact which also placed her at risk for problems in communication.

Indications of optimal coping with this crisis point are the patient's return to school, training program, or job appropriate to his physical capacity. This is evidence that the patient has embraced the reality principle and is now engaged in activities commensurate with long term planning. The family's willingness to enhance the patient's return to appropriate responsibilites in home, school, and social situations is also an indicaton of their coping with this crisis point.

VI. Recurrence

Recurrence or relapse of the disease is the sixth crisis point. Many families state they experience this as worse than the crisis of diagnosis. It recapitulates the earlier stress, but often with diminished hope for long term survival. The challenge to the family is to be able to confront their despair and helplessness in the face of the destructive power of the disease and yet restore hope for a prolonged remission and reinvest in a rigorous treatment protocol. It is indeed an awesome task. This crisis point is often also experienced as the most difficult one by the hospital staff who struggle to cope with feelings of professional failure and personal disappointment. From this crisis point on, interventions move increasingly from the practical and social to the therapeutic.

The mental health tasks are: (1) To facilitate the family's processing of information and communication about the patient's new

situation by all family members. Both the patient and the siblings may be in different developmental stages since the diagnosis, and require updated information; (2) to assist the family in regaining a life focus and time perspective appropriate to the changed prognosis; (3) to alleviate parental guilt or self blame by such means as affirming family strengths demonstrated in coping with earlier crisis points; and, (4) to help solve practical problems related to re-induction of treatment.

While family members must work through their feelings about the changed prognosis, they must not begin mourning, because the patient may well go into remission and have several more years of survival. It is essential that both patient and family maintain an appropriate, even optimistic time perspective.

Four year old Carl had been treated for A.L.L. for over two years when he unexpectedly relapsed. When told this shocking news, his mother, a nurse, turned to her husband and cried "Oh, he has only a month to live!" Careful discussion with the physician helped her to see that, although the relapse was indeed a serious thing, chances of Carl's attaining a second prolonged remission were excellent. The mother sought out the social worker she had known during the initial diagnostic phase and used her contact to review her experience then and sort out her feelings now. She recognized also that Carl had grown from a toddler to a preschooler and that he needed a better explanation of his illness, as did his older siblings.

Families who are unrealistically pessimistic may demonstrate this by giving in totally to the pleasure principle, setting no limits on their child's behavior with disastrous consequences for his reentry into normal living.

Families particularly vulnerable to this stage are families who are unrealistically optimistic but more usually overly pessimistic about the disease process. Such families may want relief from the dejection and tiredness by some closure. "I wish it were over with." This process of decathecting may be enhanced if the child's condition is acutely critical. In our experience, rapid intervention by the social worker is essential to avoid further withdrawal of the family's involvement with the child.

Indication that the family is coping with this stage includes an ability to respond emotionally to the altered prognosis the recurrence suggests, but then a reinvestment in planning for the next treatment. Such planning involves reorganization requiring a repetition of alterations undergone in the first treatment phases.

VII. Initiation of Research Treatment

The initiation of research treatment is an especially stressful time for families. The side effects and outcome of research drugs are unpredictable, and the disease is now clearly uncontrolled. The medical situation may often change, requiring the child to be hospitalized unpredictably, either with disease related problems or toxicity. Home life may become quite tenuous and chaotic. Every minor stress is magnified and there is great tension.

Five year old Bert experienced his fourth relapse of A.L.L. and was placed on Phase I drugs. His mother described "a cold hard feeling in my stomach, an absolute certainty that now things are really bad." Bert came daily to clinic, and was often admitted to the hospital although, when leaving home that morning, he and mother had expected to be able to return home. When they did go home, it was often late afternoon by the time they arrived, only to get up again the next morning and repeat the process. Bert's eight year old sister, Karen, developed stomach aches and refused to go to school. She was seen by the social worker who found that Karen did not want to go to school because each day she feared that she would return home and would find Bert and Mommy gone. She admitted being afraid that Bert would die and that, by not being home, she would be in even less control of the situation. She was reassured by the social worker that Bert was indeed very sick, but not dying yet, and that when things got that bad, she would be told ahead of time. This promise was reiterated with the mother present, who concurred. The social worker also planned with the mother for Karen to go to a friend's house after school when she and Bert were either delayed or admitted, so that she would not be at home alone.

The mental health focus now is on maintaining and strengthening communication between staff and family and between family members. The worker must (1) make every effort to find some order in this chaos, (2) explore other supports for family (neighbors, relative, etc.) who can provide concrete and emotional relief, (3) interpret the family's behavior to staff as reactive to their loss of control in order to minimize alienation between staff and parents, (4) recognize that staff may also feel out of control and perhaps guilty and offer support to them, and (5) she may need to have joint conferences with family, mental health worker, and other staff regarding daily management.

What can surprise staff is that families who have coped well during other crises points may now begin to experience difficulties. Families whose ability to control and structure has been a strength, can be especially stressed by the rapid vacillations in their child's condition and the inability to maintain a schedule or to predict changes. Now also the psychotic or borderline family member may require an unusual amount of time (as much as two - three hours

per day) to be able to cope with the rapid changes without psychotic deterioration and fragmentation or borderline splitting behaviors.

Important interventions include arranging respite care for the family and facilitating appropriate expressions of anger by the family in order to minimize displacement on to each other and to the hospital staff.

Indicators of families doing well are (1) those who are able to ventilate their anger rather than being focused on blaming others, (2) families who maintain open lines of communication with staff and avoid miscommunications, and (3) those who may be able to understand the increased stress on staff and have some tolerance for alterations in their behavior as well.

VIII. Termination of Treatment and Terminal Illness

Finally, the decision is made to terminate active treatment. It is easier for the family if the suggestion for termination is initiated by the medical staff. For all families, guilt needs to be relieved by helping them to see that they have done everything they could do and that this is not their failure. Treatment has failed, not the patient, parent, or hospital staff. At this point the mental health worker anticipates with the family what lies ahead, explores with them what they want now for their child and identifies alternative ways of achieving their goals. The crisis point of terminal illness requires continued intensive mental health intervention as the family determines where the child will die and how this will be managed by them. The parents reflect on the needs and wishes of the patient, the siblings, and themselves in order to make this decision. Do they want the child to die at home or in the hospital?

Twelve year old Alan, had had osteogenic sarcoma since age seven, and had an amputation of his leg, and years of chemotherapy, but now had progressive metastatic disease. He and his family had appropriate difficulties at each crisis point, but with counselling, successfully coped with each. When he became terminally ill, his parents had some difficulty integrating this knowledge, as they had become accustomed to always trying "one more drug." Several joint conferences with the social worker and physician helped to clarify that there were no more drugs and that our goal now was to make Alan comfortable.

The parents wanted to have Alan at home. They were frightened, but responded positively to discussions with the social worker focused on their competence, which had been well-demonstrated for five years. Alan himself rejected this idea, on the grounds that he might be uncomfortable or have pain, and might not be "safe" at home. He finally accepted the plan for Visiting Nurse Service

(VNS) to visit daily, for appropriate equipment to be obtained, and for pain control to be managed. He and the parents understood that at any time they could call or return to Memorial Hospital, or could go to a local hospital.

Alan was sent home with the plan just described, plus three times a week phone contact by the social worker. Within the first three days, he was rushed twice, at his insistence, to a local hospital. On the fifth day, the VNS called to communicate that Alan himself had been calling the VNS many times during the last two nights after his parents were in bed. He was described as "in a panic," calling to say that he was unable to breathe. Each time, when the nurse rushed to his house, he was breathing fine, but upset. He could not verbalize what he was upset about.

At the same time of this call from VNS, Alan demanded to be brought to Memorial Hospital. He requested admission stating flatly that, although he was glad to be with his parents, his brother and sister, and his dog, he could not be managed at home. He was admitted on his 13th birthday, saying, "Now I am with my family and my friends. This is where I belong for my unlucky number."

Over the next few days, conversation with Alan revealed his deep worry over his impending death. He asked, "What will it be like when I stop breathing?" and wondered if suffering made it easier to get into heaven. His questions were answered as clearly as possible, and he received much support and reassurance from staff and parents. At this time, the parents used the social worker to talk about their sadness, their pride in their son, the things that made him special, and how hard it would be to be without him, as well as their concerns about his siblings, who visited daily. Alan died five days after admission with his whole family at his side. Follow-up contact at one week and four weeks afterwards found the family still appropriately upset and attempting to cope with their loss.

Indications that the family is coping well include: (1) a focus on the daily comfort of the child and an ability to respond to his needs, (2) appropriate expressions of grief, (3) a concern about the total family unit and its future, and (4) good communication with the staff and among the family members.

Parents often have many questions at this time about how these events have been managed by other patients and families. What problems can they anticipate when taking alternative courses of action such as taking their child home? How should they talk with and include siblings and other relatives and friends? The mental health worker reviews the treatment of the illness with the family, emphasizing their strength and competence in supporting the patient

through previous crises which can be expected to sustain them now. She facilitates anticipatory grieving when possible by reviewing with them the child as a person, sharing memories, and listening to them talk of their child's importance to them. They may be helped to anticipate the loss, the empty place at the table, the bed, etc. If the patient is dying in hospital, the family may request that the worker spend brief periods daily sitting in the room with the child and family in order to help them by sharing their experience of observing the terminally ill child and then longer periods helping them plan and facilitate the anticipatory grieving process.

Vulnerable patients and families during this crises are similar to those in the previous one: (1) those who cannot contain their anger and grief and who blame each other or hospital staff, thus limiting the strength and support they can obtain from those who want to help them and (2) the most psychologically disturbed patients who cannot tolerate such a painful loss without fragmentation.

SUMMARY

We have presented two perspectives on the psychosocial treatment of pediatric cancer patients and their families. First, the psychopathological continuum which includes a small number of patients with severe psychopathology, a much larger group of vulnerable patients and families, and a normal group. Each requires a different level of intervention and techniques. Secondly, we have presented eight stress points during the course of cancer and its treatment. Both the pathological and vulnerable patient and family need to be actively monitored at these stress points using the identified therapeutic strategies.

In conclusion, I would just like to draw a distinction between the essential and the optimal psychosocial care of patients. In this paper, we have highlighted the essential. However, we are left uneasy because of our clinical sense bolstered by random interviews with families not receiving mental health interventions and responses to surveys which underscores Koocher's (1981) findings from long term survivors--namely, that even the most normal families can be helped by mental health interventions. As one of the normal mothers wrote "We were able to cope, but I think with help it could have been much more tolerable."

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THE CRISIS OF SURVIVAL: DISCUSSION OF MRS. CHRIST'S AND MS. ADAMS' PAPER

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The presentation by Christ and Adams is a well-thought-out and impressive blueprint for psychosocial interventions with the families of childhood cancer patients. Using the eight points they cite as a guide, it is not difficult to target specialized psychotherapeutic interventions to the families most in need of these services. The only improvement I can offer to this excellent paper is a suggested extension of five more points, dealing specifically with those children who are destined to be long-term survivors and those families who will not be so fortunate.

A ninth crisis point would be what I shall call anniversary phenomena. That is to say, even after the cessation of successful treatment, the cancer patient and family members may face renewed stress at certain anniversary times which recall events related to the illness. If, for example, the diagnosis occurred just before a holiday or during summer vacation, the return of this event each year might elicit a renewed bout of anxiety. The individuals involved may not even realize the source at the time it occurs.

A tenth crisis point would be special "lump" or symptom consciousness. That is to say, a return of symptoms similar to those which preceded the diagnosis of cancer (e.g., swollen glands, feeling of lethargy, a new lump somewhere) may also generate a round of intense anxiety. The anxiety may persist, even when reassurances that the new symptoms are not a sign of malignancy are offered.

An eleventh crisis revolves around developmental marker events. These are social or achievement events which serve to underscore progress or growth, thereby reminding the patient and family of the future and recalling some feelings of uncertainty. For example,

high school graduation, a wedding, a twenty-first birthday, or some similar event normally seen as a developmental or life milestone event may call up feelings of insecurity and uncertainty about the future in individuals who had apparently put aside thoughts about potential disease recurrence.

The twelfth stress point I would add is that of encountering societal prejudices. When friends and neighbors learn that someone has cancer, the reactions may range from support to avoidance. Occasionally, the avoidance stems from fantasies of contagion. Concerns based on the assumption that the cancer patient will certainly die soon are also quite common. In the workplace, this may result in ostracism or actual denial of employment to a childhood cancer survivor reaching healthy adulthood. The U.S. military, for example, automatically rejected three of our long-term survivors who attempted to enlist despite the fact that they had all been treated for cancer in infancy and were quite healthy some sixteen years later when they attempted enlistment. The patient or family who has been coping well may experience renewed anxiety when encountering this type of reaction years later, even though the reaction itself is based on prejudice more than rational fact.

The thirteenth and final point I would make note of as a special emotional crisis time is the period several months after the death of the pediatric cancer patient who does not survive. Generally, the surviving family members will be the recipients of much support in the first several weeks after the loss. By four to five months later, however, friends and those relatives beyond the immediate family may not understand why the immediate family has not "gotten over" the loss. The advent of the deceased's birth date, a family occasion or holiday, or some similar event may well draw out renewed mourning or grief reactions in the survivors. Unfortunately, this often occurs at a time when significant sources of support outside of the home are not as available as they were at the time of the death. Often the former caretakers of the child (the nurses, physicians, or psychosocial staff) would be the ideal contacts for the family at this point in time, since they know exactly what the family went through and can be less prone to avoid the topics of concern than people in the community. Too often the family members believe that they cannot or should not "bother" the staff, since the child is now dead and hence the reason for relating to the staff is ended.

It should be clear that this thirteenth crisis requires substantial outreach by the oncology team for the best chance at resolution. One can offer the family this opportunity shortly after the child's death, but it is also good to offer it again several months later as an anniversary of the child's birth or family holiday such as Thanksgiving arriving. I would also recommend still another reaching out at the one year anniversary of the child's

death.

In addition to the five points I have added, I would also like to underscore three of the messages provided by Christ and Adams. The first of these is their suggestion that the family be engaged in predicting who they will cope with future crises during treatment. We psychologists call that concept "cognitive rehearsal" or "stress innoculation." The point is that this activity is of major help later as the stresses do occur. The patient and family feel forewarned and prepared, so they are able to adapt more effectively even if the actual medical outcome was unalterable.

A second point stressed by Christ and Adams was the notion that a speedy reintegration to school and resumption of normal activities is important for the child with cancer. This is indeed of critical importance as a study in progress at San Diego State University by Dr. John Spinetta has been demonstrating. The maintainence of "normality" as much as possible is central to the adaptation process and prevents unnecessary social withdrawal and depression.

The final point I would underscore is that raised by Christ and Adams under the topic of "relapse." It is important to avoid giving the patient a "blame" message at such times. Patients and their families are both happy and somewhat proud as they are able to fight the terrible disease that is cancer. When the diagnosis is first made, the patient and parents often wonder if it came because of something they had done or not done. The relapse provides a second opportunity for some magical thinking and self-blame on that score. Reassurance by the staff is of great importance, even if there are no direct expressions of guilt feelings about the relapse.

I consider these comments to be a mere elaboration on a very excellent paper, and I would note with gratitude the service that Christ and Adams have performed. Even the novice arriving at a cancer facility (nurse, physician, or mental health professional) will be able to use this material as a guide for targeting intervention most effectively.

HUMAN RESPONSES TO CANCER: AN ECOLOGICAL APPROACH

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For those of us who have had personal or professional experience with cancer patients and their families, it is clear that this diagnosis precipitates a number of serious psychosocial problems. These problems may be resolved, mitigated, or aggravated as the result of a complex process of adaptation involving the patient, family and the health care system. The thesis of this presentation is that the problems associated with cancer, if treated early as problems of adaptation, will respond to interventions specifically designed for them. Problems of adaptation are likely to become ingrained personality difficulties if they are not treated promptly with appropriate brief interventions.

Some of the commonly observed problems associated with cancer include: (1) long and dangerous delays in evaluating suspicious symptoms and lesions or instituting treatment for the disease. Persistent refusals to acknowledge the existence of the disease, its chronicity or its fatal potential; (2) physical and mental exhaustion in family members, including instances of drug/alcohol dependence and psychiatric casualties. Occasionally, one observes the abandonment of the patient in hospital before he is ready to die; (3) poor management of precious family resources spent in a vain search for miracle cures or the result of unnecessary changes that add to already high stress levels, e.g., impulsive pregnancies, divorces, job and residential moves, etc.

It is also apparent that these problems are not distributed evenly among patients and their families. A minority emerge intact from the cancer experience, but not without much pain and suffering, while many more people are overwhelmed by the illness and suffer long term damage years after the patient's death. How can we

account for the fact that some families manage to cope with their problems while others bear the scars of the cancer experience for the rest of their lives?

Personality theory has long dominated thinking about stress, offering us an explanation for the uneven distribution of psychosocial problems that is widely held by lay as well as by professional persons. According to this theory, human responses to cancer are predetermined by individual history as that history is revealed through personality. The evidence that is available, however, in the form of actual attempts to predict stress performance based upon personality assessments, has not proven successful. For example, in two attempts to predict individual stress performance overseas, under combat and peace corps conditions, psychiatric evaluations were unable to forecast outcome successfully. Moreover, the performance findings were skewed in opposite directions; under combat conditions, most of those soldiers who were expected to do poorly, actually performed well, while many peace corps volunteers who were expected to do well, did poorly (Aita, 1949). The evidence indicates that personality assessment is a poor predictor of human stress reactions. While personality influences stress reactions, it does not dictate how people will respond. Other factors, specifically, current situational forces, must be taken into account to understand fully stress responses.

There are other drawbacks to espousing personality theory where stress behavior is concerned, apart from the fact that this theory does not have good predictive power; personality theory fosters an attitude of pessimism and apathy toward the whole subject of stress behavior and to the clinician's hope of modifying maladaptive stress behavior with brief interventions that are not designed to alter personality. Personality theory calls for the long term treatment of individual character in order to affect stress behavior; unfortunately, maladaptive behavior under stress conditions is manifested within days after the diagnosis of cancer. Many nonadaptive decisions are made in crisis that are irreversible thereafter. Personality treatment, even when successful, does not have any bearing on current stress situations simply because it takes so long to change human character. Traditional psychotherapy misses the opportunity to make interventions at the outset of stress reactions when such interventions are of critical importance.

Personality theory also discourages the investigation of stress behavior, particularly of the part played by environmental forces which, in fact, do shape stress reactions (Glass, 1954). In short, our ability to resolve or mitigate the psychosocial problems associated with cancer is severely limited if we look solely to the individual for their solution. The situation is comparable to the dilemma we would face if we sought to reduce traffic accidents by holding the driver solely responsible for them. The remedial

activity possible under the theory of driver responsibility is limited to the selection of drivers and to training them in safe driving procedures. The construction of autos that include safety features, the enforcement of traffic and speeding regulations, the promotion of alternative means of mass transportation are all activities that would not receive attention under the theory of driver accident responsibility.

Clearly, the one-sided emphasis on the individual that excludes serious consideration of environmental factors in understanding and modifying stress behavior sharply reduces the potential for prevention and the clinical opportunities offered by brief interventions that are concerned with individual adaptation. In short, embracing personality theory to account for stress behavior is not a benign decision.

In contrast, an ecological approach to human stress behavior offers the possibility of achieving considerable preventive and clinical benefit from interventions that are brief and applicable early under stress conditions. These interventions are designed to influence the process of individual adaptation itself, including the behavior of family and health care system members, whose actions are a vital component of that process.

The diagnosis of cancer precipitates a current, brief struggle in which the individual attempts to come to terms with a new set of highly disruptive circumstances. This adaptive process is essentially a problem-solving experience concerned with the resolution of empirically identifiable, common yet specific coping tasks posed by each form of cancer. Adaptation involves cognitive, emotional and decision-making activities which take place in a social context, in an arena in which interpersonal phenomena strongly influence the individual struggling to adapt effectively. Individual adaptation to cancer is shaped by relatives, friends, peers and by health systems' policies and personnel whose behavior has a dramatic impact on the cancer patient.

Stress interventions are concerned not only with the patient directly affected by the diagnosis of cancer, but with all those in the family and the community who influence the patient. Of all interventions, those that are intended to alter systems and system personnel have the greatest potential for affecting individual adaptation at the least cost.

The effectiveness of professional interventions with the psychosocial problems generated by cancer is dependent upon having detailed knowledge of the process of individual adaptation. What are the different coping tasks posed by breast, lung, colon and uterine cancers? What specific behaviors are required to resolve

these tasks effectively? Which decisions promote successful problem-solving and which decisions do not? What roles do families and health care systems play that promote or block effective individual adaptation? What are the different types of intervention that are possible in an ecological model? How are these interventions integrated and coordinated to achieve the goal of promoting effective individual adaptation?

Reactions to cancer are not uniform responses to a single disease. Each type of cancer, e.g., lung, colon, breast, uterine, etc. has special meaning and implications for its patients and different consequences as well. Each form of cancer affects the body as differently as does cancer treatment.

Within a particular type of cancer (e.g., breast cancer), the meaning of the disease varies in relation to the individual's stage of development and the position she occupies in the family life cycle. Women with breast cancer in their 20s and early 30s who have not yet established families and who want to do so, worry about their ability to have children and normal sex relations after treatment. Those in their late 30s and 40s who have husbands and dependent children, worry about who will care for the children if they should die and whether they will continue to have normal sex relations if they survive. Finally, breast cancer means something else to a woman in her 50s or 60s whose children are independent and whose sex life may be tapering off or nonexistent.

Having noted that a particular form of cancer will have special meaning to subgroups with that diagnosis and that particular meanings are associated with each separate form of cancer, it is also necessary to point out that all cancer patients are confronted with certain common issues: (1) with the fact that a disease exists that must be individually interpreted as to its curability, chronicity, and prognosis; and (2) with the impact of the disease on body and self-image and its effect on normal functioning and responsibilities. Needless to say, there are differences between patients in the way each person resolves these issues that have direct implications for psychosocial outcome.

For those patients who have families, still other questions need to be answered: Who should be told about the diagnosis? What should be said about it to adults and to children? When should family members be told about the disease? By whom? What is the family's care responsibility for the patient and for other members of the family? What preparations need to be made for living with a cancer member whose life span and level of functioning are uncertain?

The remainder of this presentation will be devoted to an exposition of an ecological approach to the problems associated with

breast cancer comparing this form of cancer with childhood leukemia and to the implications of this approach for intervention.

While this exposition of an ecological approach relies heavily on the experience with an adult form of cancer (i.e., breast) the implications for comparable interventions in childhood cancer are both real and relevant. In both adult and child cancers, ecological interventions take a variety of forms, e.g., providing information for patient and family, individual and family focused treatment and system interventions. All interventions are based upon an intimate and detailed understanding of the coping tasks of the particular cancer experience beginning with the patient's or family's recognition of bodily changes, symptoms, diagnosis and the early phases of treatment.

The development of a malignant breast lesion requires each patient to respond to a specific set of coping tasks. The breast cancer tasks include:

(1) Recognizing the existence of a lesion and obtaining early medical evaluation.

(2) Accepting some form of medical treatment without lengthy delay.

(3) Coming to terms with bodily disfigurement as a result of treatment.

(4) Accepting cancer as a chronic, potentially fatal disease.

(5) Maintaining open communication about the disease with all members of the family.

The failure to recognize or to take effective action vis-a-vis any of these tasks constitutes a form of decision nevertheless.

Obviously, breast cancer involves an adult who has considerably more potential for coping independently than a leukemic child who must rely heavily on parents to help him resolve cancer coping tasks. But the breast cancer adult does not cope in isolation and is influenced, sometimes decisively, by her sex partner and by others in and outside the family.

Recognizing the existence of a breast lesion and obtaining an early medical evaluation (task #1) is largely the patient's responsibility, but even here, the woman's behavior can be influenced by family members and by her own level of knowledge about breast abnormalities. Many women do not recognize these lumps until they become quite large, e.g., the size of a plum. Some women do not realize the potential danger of such lesions (despite the publicity given to this symptom) and, consequently, are under no compulsion

to do anything about them. Others fail to report the lesion to anyone, including physicians or family members, for unconscionably long periods, adopting a "wait and see" attitude, hoping the lump will disappear by itself or as a result of some home remedy.

It is important to recognize the existence of breast lesions as early as possible and to have them examined quickly while they may still be localized growths that have not yet spread to other parts of the body. Leukemia, unlike breast cancer, is a systemic disease and while early treatment is important, it is not possible to treat leukemia as a local manifestation.

In some instances it is the sex partner who first recognizes a breast abnormality and, occasionally, despite the fact that another person notices a breast change, the woman may still deny its existence. In other cases, an adolescent daughter or friend first notices an abnormal nipple formation and urges the patient to see a physician. But not all members of the family encourage early medical assessment. Women with a history of benign growths may have husbands who discourage additional examination in the mistaken belief that the latest lesion will also prove to be benign.

In this initial stage of breast cancer recognition when the lesion is still a private, unreported discovery, intervention consists of educating susceptible women and family members about the importance of medical evaluation. Health education so far has not proven to be a roaring success. In this respect, we have much to learn about convincing women to conduct breast self examinations, early case finding and self-referral. The decisions made at this time to hide or reveal an abnormality are critical to the future of the patient.

Accepting medical treatment without lengthy delay (task #2) might appear, at first, to be a simple matter once a physician is involved in lump evaluation. The patient merely follows the recommendation of the medical expert who most of us assume knows what is best for the patient. In fact, treatment recommendations and case management are moot issues among surgeons who may favor one view or another of how to proceed in the treatment of breast cancer.

A woman who reports a suspicious breast lump to her physician is usually referred to a surgeon for further evaluation and treatment. For over 75 years, surgeons treated breast cancer with one remarkably uniform method, i.e., immediate, radical mastectomy. But within the past ten years, surgeons who treat breast cancer have developed widely varying views and approaches to cancer treatment and to patient management. The treatment recommended may be minimally disfiguring (lumpectomy) or involve drastic physical changes (radical mastectomy). The patient may be urged to submit to immediate, one stage surgery with little opportunity to prepare

herself or her family for the diagnosis and treatment, or she may be allowed to elect two stage surgery which gives her more time to realize what is happening and to prepare for the illness and the treatment experience. The patient may be urged to trust the surgeon to make all necessary decisions without her participation or she may be given a good deal of information about treatment options, including breast reconstruction, and urged to participate in deciding the kind of treatment she will experience.

The differences in treatment and patient management outlined above have a profound impact on psychosocial outcome for the breast cancer patient (Kaplan and Grandstaff, 1979a). But whether a woman gets to one type of surgeon or another is largely a matter of chance. Her own physician is apt to recommend a surgeon because he has a good reputation as a competent and skillful surgeon for whatever surgery he performs. In most instances, the referring physician, who may not see many patients with breast lumps, is simply not aware of all the considerations that should be taken into account in recommending a surgeon.

Under considerable duress, the patient usually decides to go along with her physician's recommendation to see a particular surgeon, largely on faith, for she does not have the information needed to make an intelligent choice on her own. And so a critical decision, the selection of a specialist, is made by a physician who may not know how to choose a surgeon who will meet his patient's needs and by the patient who acquiesces but does not participate in this choice.

While most treatment delays are attributable to the woman or to her family, a physician can mistakenly judge a lesion to be benign when it is malignant and recommend no treatment in favor of another exam in six months or a year while the cancer is left to grow unattended and to spread (Rollin, 1976).

Intervention at this stage should take several forms: (1) Educating the patient/family to realize that surgical practice varies, stressing the importance of a second opinion before coming to a treatment decision; and, (2) educating health personnel, particularly physicians, in the psychosocial aspects of breast cancer so that they will encourage patient participation in disease treatment. In any event, treatment decisions should not be put off for lengthy periods so that the patient will have the best chance for treatment success. Again, breast cancer is unlike leukemia in that there are a variety of treatment options to be considered while the treatment of leukemia is more uniform with fewer options.

Coming to terms with bodily disfigurement as a result of treatment (task #3) is still a necessity for the large majority of women with breast cancer. While surgery is moving rapidly away from

radical procedures to less disfiguring surgery in conjunction with other treatments, most women are confronted after surgery with bodies that are drastically altered by breast amputation. They must be able to come to terms with significant changes in body image and self-concept before they can resume living with spouses as women who feel feminine and are interested in sex relations once again.

Disfigurement is also part of the leukemic child's experience, but body changes are a temporary result of treatment including loss of hair and bloating of facial features. Both of these changes disappear when chemotherapy is ended. Children are upset by these effects of treatment, particularly adolescents, but since most children with leukemia do not have active sex lives, bodily changes do not have the same interpersonal impact that amputation has for the woman with breast cancer.

Accepting cancer as a chronic disease (task #4) is a particularly important task because 50-75% of breast cancer recurs even after the magical five years free from disease has elapsed. The breast cancer patient must learn to live for the rest of her life with a chronic disease that can recur and cause her death. Many well meaning surgeons reassure their patients that they "got all the cancer" after the mastectomy. This comment is usually interpreted by the patient to mean that she is cured and need not continue to be vigilant about breast self-examination. When promised cures give way to recurrences, the trust in one's physician also goes and resentment takes its place. It is important to caution surgeons about the risks involved in giving questionable assurances that promote unrealistic hopes.

Accepting bodily disfigurement and the chronicity of cancer are the central tasks once the lesion is reported to a physician. Successful resolution implies accepting these two concerns as realities that one must be prepared to live with, not to like. If these issues are denied or not resolved prior to surgery, for any reasons, the full rehabilitation of the woman may not be achieved or may be delayed for years even when the prognosis of the illness itself is a favorable one.

Why is it so important to achieve a substantial resolution of these two problems before surgery? In the course of any crisis, one's normal activities and responsibilities vis-a-vis others are suspended while the individual is given a brief time to solve new problems, to come to terms with one's reality, and a new set of circumstances imposed by a serious illness.

Whether a woman can achieve the resumption of most of her responsibilities, consistent with the limitations of having a

serious disease, depends upon how quickly and how successfully she comes to terms with her new self. Many women do resume highly satisfying lives within weeks of lump discovery despite the fact that they no longer have intact, healthy bodies and have to live with the knowledge of possible recurrence of a life-threatening disease for the rest of their lives. Many women do not (Rollin, 1976).

If these coping tasks of acceptance of disfigurement and of the disease's threat to life are not resolved before surgery, it will be extremely difficult for the woman to take up the job of fashioning a new life, part of which involves picking up old responsibilities and activities. The longer one is preoccupied with tasks that need to be resolved effectively and quickly, the greater is the risk that important activities and relationships may deteriorate or be lost altogether. A woman, for example, who cannot accept the fact of disfigurement before surgery will not be able to resume sexual relations with any measure of pleasurable anticipation or satisfaction for herself or her partner. The woman who fails to resolve successfully these particular coping tasks early is apt to be preoccupied and/or inhibited by these problems until they are resolved. She will be unable to pick up the pieces of her life and put them together into a new, viable and satisfying way of living (Rollin, 1976).

Unfortunately, one does not have unlimited time to resolve threatening and disruptive changes. Nature abhors the vacuum created by an illness and permits only a temporary suspension of one's normal responsibilities of being a wife, a mother, etc. If the vacuum is not filled within a fairly brief period of time, family and community relations that existed prior to the illness may never again be reconstituted or if they are resumed, may continue only in attenuated and unsatisfying forms (Rollin, 1976).

There are a number of accounts written by women who have had breast cancer describing their particular experiences and their efforts to cope with the disease and its implications. Two of these reports will be reviewed to illustrate the problem-solving approach to adaptation described in this paper (Kaplan and Grandstaff, 1979b).

> Mrs. B. reports that she had been in the habit of routinely examining her breasts for years before she discovered a lump. She had grown children at the time. She had just been sworn in as Special Assistant to the President's Council on Environmental Quality and was about to represent the United States in Moscow for the meetings of a joint USA-USSR committee on environmental protection. She immediately saw her personal physician who recommended

further examination by a surgeon although he thought the lump was probably benign. Since Mrs. B had no sense of concern at that time and had a full work schedule, she and the surgeon agreed to do the biopsy after her return in six weeks from her European trip. She told no one else about her lump but went on to make the planned trip.

While abroad, she experienced pain and burning sensations in her breast and she began to be worried. Surreptitiously, after her return home, she read about breast cancer and asked her brother, a hospital administrator, for information. She did not wish to alarm her family, particularly her mother. She found it difficult to talk to her husband but she felt he should be prepared for the possibility of cancer which she was beginning to think about seriously. She was told in her initial medical examination that the chances of finding a benign lump were 60 to 40 in her favor. But now she began to face the fact, with her husband, that the tumor might be malignant, no longer comforted by the 6 to 4 odds, presumably, in her favor.

By the time she entered the hospital for the biopsy, she felt apprehensive. She recalled several close friends, three of whom had died because the cancer was not found in time and several others who had had a mastectomy and survived. One friend had signed papers without understanding she had given permission for a mastectomy. She only expected a biopsy. Mrs. B decided to have two-stage surgery in the event of malignancy. Her physicians outlined the surgical choices, favoring a modified radical mastectomy. Mrs. B elected to have a simple mastectomy with nodal dissection (which is a modified mastectomy) on the assumption that the cancer had probably not spread to the lymph glands and, at this point, in considering the type of surgery she could elect she also faced the possibility that her life might be shortened if the malignancy had metastasized. In that event, she decided she "would live as long as she was supposed to." Her biopsy was positive and when she recovered she began to accept the fact that she had cancer and the imminent loss of her breast. She cried for the first time, alone, and later with her two daughters as she recovered from the biopsy surgery in the hospital.

Fortunately, the pathology report following

> surgery indicated no nodal involvement. After the mastectomy, Mrs. B decided, with her family's agreement, to write about her experience for the benefit of other women. She concluded her account by attributing her good psychological recovery to her family's support during the "unexpected, traumatic experiences of the last several weeks" (Black, 1973).

Mrs. B's early decisions to put off surgery so that she might attend the Moscow conference and her failure to inform any family members of her predicament are not examples of effective coping. On the contrary, these decisions reflect her early failure to prepare herself or others for the possibility of malignancy and breast amputation. Apparently, these early decisions reflected less an inability to face unpleasant reality than an understandable desire to accomplish an important and unique work assignment. Mrs. B demonstrated her ability to cope effectively once her government assignment was out of the way.

While she wisely sought medical advice before her trip abroad, her failure to enlarge the circle of those informed of her lesion at that time may well have served the function of lessening the chances that someone might have sought to dissuade her from her trip.

Once she returned from abroad, her coping efforts improved considerably. She began to prepare herself and others in the family for a possible diagnosis of cancer. She achieved this preparation by electing two-stage surgery which gave her further time to come to terms with cancer and her disfigurement following surgery. She mourned the loss of her health to a chronic disease with its ever-present threat of death and the loss of her intact body as a result of breast amputation. Had she chosen one-stage surgery instead, Mrs. B might not have provided the time she and her family needed to prepare for her cancer. Fortunately, her family responded with realistic and firm support to which Mrs. B correctly attributed an important part of her good psychological recovery from her trauma.

The second personal account of the breast cancer experience is more detailed and gives us the opportunity of reviewing another woman's early coping patterns along with outcome revealed months after surgery.

> Ms. R's husband discovered her breast lump during sexual intercourse. She was 38 years old at the time, with no children. She went immediately to her physician who, after examining her mammograms decided there was no need to worry. He diagnosed the lump as a benign cyst.

Almost a year after her first examination, Ms. R, following her physician's earlier recommendation, returned for a second medical examination. Her decision to return was influenced by the publicity given to Mrs. Ford's and Mrs. Rockefeller's mastectomies and the realization that early detection could save one's life. This time, the mammography examination prompted her physician to recommend that the lump be surgically removed. Ms. R, fleetingly, thought about the word "cancer" but dismissed this diagnosis as a real possibility. She was convinced by her history of excellent health and a strong sense of invulnerability that the biopsy was merely a "nuisance interruption." She did little, if anything, to anticipate possible bad news from a biopsy.

Ms. R later wondered at her being so "pigheadedly unafraid" prior to surgery but she was convinced at that time that "bad things don't happen to me." Prior to seeing the surgeon, she acknowledged that she had not come to terms "with what might happen to me." She could not seriously worry about something that probably wouldn't happen. She reminded herself of the odds, 10 to 1 in favor of the lump being benign.

The surgeon told her, following his exam, that there was a "good chance of a malignancy"; Ms. R reacted with shock to this news. She came very close to fainting. She cried briefly but after leaving the surgeon's office, she reminded her husband that "it still might not happen." During the weekend of waiting for surgery scheduled for the following Monday, Ms. R decided that keeping busy ("with trivia") would best get her through the waiting period. She shopped and spent time with friends. She left instructions for her husband to tell her parents only if cancer was discovered. She did get as far, psychologically, as fearing the loss of her breast. Her husband, she realized later, had gone beyond that to consider that she might die as the result of cancer. She did not consider any issue other than her fear of breast loss nor did she accept emotionally the possibility of breast loss prior to surgery.

The evening before surgery, her surgeon discussed possible options should the biopsy prove positive. He recommended a "modified radical" and gave Ms. R the choice of one or two-stage surgery. She thought the

two-stage surgery was "stupid" and gave the surgeon permission to do what he thought best. Her uppermost concerns, at this point, were her fears of not surviving surgery and of disfigurement.

In the days of hospitalization after surgery, Ms. R enjoyed the attention and concern of many friends. She acted bravely and cheerfully, playing the part of Pollyanna with visitors. She enjoyed, particularly, visits from an old suitor who indicated his continued, serious interest in her. But she rejected a visit from a Reach-to-Recovery volunteer.

She refused to look at the breast wound, realizing that to do so would shatter her precarious "tough" pose. In the hospital, she "didn't feel much of anything." In her own words, she realized intellectually what happened but not emotionally. Even the good news from pathology indicating that her lymph nodes were clear brought little reaction from her--a numbness of all feelings characterized her during the hospital stay of eight days.

The first night at home was the occasion for an abortive attempt at lovemaking. She endured sex because her "husband needed it" but the effort ended disastrously when he felt her intact breast. The next day the bottom fell out of her "brave" act. She realized that she was not healthy any more. Her chances for long term survival had dropped from 96% to 80%. She was very angry that the lump had not been taken out a year earlier. Finally, for the first time since the operation she began to cry. She became acutely aware of the possibility of dying of cancer and sought comfort from her husband, she continued to cry profusely. Finally, Ms. R realized that the fear of dying must be borne--that there was no alternative to bearing this fear. She felt rage, self-pity and frailty, feelings she had not experienced earlier.

Sex with her husband was something she continued to dread because she no longer found herself attractive. She felt deformed and that killed any sex urge she might have had. She continued to be unable to look at her wound. She made a tentative visit to obtain a breast prosthesis and was so upset at the prospect of wearing one that a month passed before she could again consider the kind of prosthesis she might prefer.

She returned to work eight days out of the hospital but this didn't work out; she felt strange and exhausted. Two weeks after surgery, she forced herself to look at her wound and found the experience devastating. She no longer slept naked as had been her custom.

While her relationship with her husband was deteriorating, she continued to become seriously involved with her old boyfriend. She was unable to let her husband see her wound for a few weeks. When she did show it to him, his attempts to reassure her did not comfort her.

One month after surgery, she left her husband to live with her old suitor. She left stealthily, without any warning or a discussion with her husband. She was aware that her marriage had not been perfect. On the other hand, she recognized that it had held real satisfaction for both partners. It was her fear of her husband's infidelity based upon earlier incidents that caused the separation. About five months later, despite continued protestations of his continuing love, her husband agreed, reluctantly, to a divorce. It was a painful experience for Ms. R. Soon after the divorce, her relation with her new partner began to go sour over his desire for children which put her at some risk of cancer recurrence. The planned marriage was delayed. Their relationship deteriorated further and finally ended eight months after it began.

Nine months after surgery, Ms. R was living with her mother after the unexpected death of her father and because she was lonely. She resumed contact with her ex-husband on a tentative basis, both considering remarriage but neither one being willing to move precipitously to reunite (Rollin, 1976).

Ms. R was unable to prepare herself for the possibility that she might have cancer before her surgery. She did not consider the prognostic implications of having cancer until she left the hospital some eight days after surgery. She got as far as contemplating breast amputation with consdierable repugnance but no acceptance. In the hospital, she repressed successfully almost all unpleasant feelings only to have these feelings, fears and frightening thoughts overwhelm her once she came home.

Sexual relations proved totally impossible because she felt herself to be physically unattractive. Again, feeling better about oneself and one's body comes in our observation only after mourning one's losses which Ms. R did achieve some months after

surgery. However, she did not achieve acceptance of her disfigured body before terminating a meaningful marriage and catapulting herself into a new relationship with another man which also fell apart after eight months.

Ms. R's decision to terminate her marriage while she was in the throes of coping with cancer and the results of her surgery violates an important coping principle, namely, that one is better advised not to make major changes in one's life until one resolves an existing crisis. The motto to follow in such situations is "don't just do something--stand there."

Perhaps, the most critical interventions consist of identifying those women who are unable to achieve task resolution on their own in the critical presurgery period and developing techniques to resolve these coping tasks as expeditiously as possible.

This goal is not unlike the situation that confronts a physician called upon to treat a child with an acute infection, e.g., septic sore throat. He must diagnose the disease and introduce antibiotics during the acute stage to prevent damage to vital organs. If suitable treatment is not instituted rapidly, the risk of complications and sequelae will increase considerably. Some significant treatment time can be gained for those women who have not made progress in their resolution of early coping tasks by electing two-stage surgery. However, the extension of time gained in this manner represents an opportunity but not a guarantee that the time will be used effectively for problem solving.

The successful resolution of breast cancer tasks means achieving long as well as short term benefits. Rollins (1976) sums up these benefits at the conclusion of her personal account of the breast cancer experience:

> Fact is, I'm the same car I always was, except now I have a dent in my fender. Of course, I tend to overdramatize some of my (mostly imagined) personality changes. The other day, for example, I was running off at the mouth about one aspect of my new character to my mother. "I'm a lot more impatient now," I said to her earnestly. "I don't want to waste time. I don't want to speak to people I don't want to speak to, or be with people I don't want to be with. I'm less polite than I used to be."
>
> "But sweetheart," said my mother gently, "you were never polite."
>
> There are some changes, though not in personality, not in character, as I would sometimes like to think,

but in the way I see certain things now, in perspective. This, I know, is trite, but it is also true: When the possibility of death is on one's mind, the problems of life, no matter how great or how niggling, loom less large. When things go well nowadays, I feel as happy as I ever felt before the operation. But the converse has altered remarkably. When things go badly, I definitely suffer less. A personal hurt, a screw-up at work--such things bother me less now, much less.

My raised consciousness about death has somewhat raised my consciousness about life. There is, I find, a recurring jingle in my head:

Am I doing
what I'd want to be doing
if I were dying?

When the answer is no, I don't always act on it, but sometimes I do. More and more I do.

I have made death's acquaintance. And however horrendous and premature that meeting was, I think it will have softened the shock of our eventually living together, whenever that happens. I hope it won't be soon. Because the peek at death has given me some new information about life, all of which has made me better at it than I was before. And, with some more practice, I could get better still. If I don't have a recurrence of cancer and die soon, all I've lost is a breast, and that's not so bad (Rollin, 1976).

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IS A MARRIAGE BETWEEN PSYCHOANALYSIS AND SYSTEMS THEORY ECOLOGICALLY SOUND? SOME PSYCHOANALYTIC PERSPECTIVES ON HUMAN RESPONSES TO CANCER IN CHILDREN: DISCUSSION OF DR. KAPLAN'S PAPER

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It was August in New York. More accurately, it was August in Brooklyn, and that is hotter still. Both the heat and the humidity approached one hundred, and Brooklyn does not provide many air-conditioned distractions from such an infernal onslaught.

That Summer marked the beginning of my second year as a Fellow in Child and Adolescent Psychiatry at the Downstate-Kings County Hospital Centers. I was assigned to our Pediatric-Liaison Consultation Service. While I would dutifully respond to calls from the Pediatric Medical and Surgical floors, I would also, between consultations, take my car for drives around the long blocks of the hospital complexes. It had one of the few accessible air-conditioners within a five-mile radius.

I was in the car. It was the middle of the day, and the heat was striking its oppressive crescendo. My beeper signalled. When I checked in, the message operator said, "Go see Ivy on B-61." I dragged myself to the Pediatric Medical Floor in the Kings County Complex. As I arrived, trying to reengage a semblance of professional presence, the nursing staff began to joke. They suggested that the entire building should be infused with mega-doses of aspirin to relieve it of the stultifying fever induced by the Summer sun. "Ivy," they nodded, and handed me a chart.

Ivy was a ten year old girl with leukemia. The diagnosis had been made two years previously, and a remission had been accomplished. She had returned home and done well until the recent end of the school year, at which time her mother noted extreme lassitude. Four weeks before I was called to see her, Ivy had been readmitted,

febrile, and with a host of pathological findings. Attempts to induce a further remission had thus far been unsuccessful. She remained febrile and had begun to appear more toxic.

Ivy was moved into what was euphemistically called the "private room" on this City Hospital pediatric ward, a small, sterile yellow-tiled room, about eight feet by ten feet--certainly an old bathroom--now used for reverse isolation.

The Pediatric Staff had tried to make the room look cheery, but their good intentions were easily wilted by the oppressive heat and the cramped quarters. The room took on a strange closet-like atmosphere, as it was overfilled with just a hospital bed, a television set, and poor pathetic Ivy. The child sweltered as a tiny electric fan moved small streams of hot air around. She was small, gaunt, and looked miserably unhappy. Islands of curly hair dotted her tiny scalp. The fan and the television were plugged into the only outlet in the room. An I-V bottle was plugged into Ivy, and Ivy was emotionally plugged into the T.V. set.

The T.V., she explained, had been her only companion for two weeks. Her mother and her aunts, her entire family, had stopped coming to see her, and she was very, very lonely. We chatted about the T.V. for awhile. The repertoire of shows provided her with minimal, but predictable companionship. Then, after a half-hour, as we were getting to know one another a bit, Ivy asked me to turn off the television. After I did so, she looked sorrowfully, but with deep resignation at me. She whimpered, "No one comes to see me anymore, except the doctors and the nurses. I think that now I am going to die forever. Can't you find my Mommy?" No more needed to be said, and I promised that I would try. At any rate, I would come back tomorrow.

I checked the chart to discover, almost predictably, that mother had no telephone. As I was about the leave the ward, I decided to ask Ivy if she had a neighbor with a phone. I returned to her room and stuck a quickly recapped and remasked head into her room. Ivy was asleep. "It'll keep," I thought. "There's always tomorrow." I doubled my pace to the elevator with renewed and refreshing thoughts of my air-conditioned car.

The following day I returned to the ward in mid-morning. When I saw that the caps and gowns were no longer outside the "private room," and the door to that old bathroom was slightly ajar, I, in total reflex, knew what I would find inside. The bed had been stripped, the mattress folded in half. The T.V. and the fan were gone. And so was Ivy. She had died in the night, and the hospital was still looking for her mother.

It occasionally still haunts me to think of that consultation

with little Ivy, of her stark and lonely last day, of her sterile death. Thus "Am I helping my patient in the best and most comprehensive way that I can? Do I understand my patient?" and "Does my patient feel understood by me?" are fundamental questions which any of us, as mental health professionals, must constantly ask as we undertake any facet of our clinical work. But, as we can understand with Ivy, and, indeed, with any child who is seriously ill, and with their families, these questions become more acute. For the normal generosity of time is no longer on our side. The emotional chaos with which a seriously ill child must cope and the anxiety that such an illness frequently induces in families forces us to keep our work deliberate and focused.

So, it is not surprising that Dr. Kaplan's paper addresses the issue of appropriate mental health care delivery to seriously ill patients and their families. Is there, Dr. Kaplan poses, a rationale for doing our work with cancer patients in a more circumscribed way, with clearer goals, and with a sensibly structured methodology?

He argues that, if we want to pursue our job well with such people, we should best approach our work from an ecological or systems point of view. Therein an invariant set of adaptive tasks confront a newly diagnosed cancer patient and his family. These tasks also define the focus of crisis intervention for the mental health professional: (1) the presenting signs and symptoms must be acknowledged and professional help must be sought; (2) the diagnosis must be accepted and treatment instituted without delay; and (3) the chronicity of the disease, the potential for its recurrence and bodily disfigurement must also be accepted. What is real and what is not real about the disease, diagnosis, prognosis, and treatment options must always be an organizing backdrop for the clinical work to be successful.

Thus, Dr. Kaplan tells us that the processes of adaptation to a commonly accepted reality become both the therapeutic objective for the patient and family and the therapeutic task of the practitioner. Resistance to the "real" must be overcome in order for optimal adaptation to ensue. These are assumptions that do merit careful scrutiny, and I will return to these points shortly.

For the moment, I want to travel with Dr. Kaplan on a brief excursion that occurs early in the course of his paper. He argues that processes of adaptation, as these are understood in a systems framework, should be the guiding force toward successful crisis or brief therapeutic work with seriously ill patients and their families. A systems, or ecological, focus on adaptation bypasses what Dr. Kaplan suggests are the failings of "personality theory," a term which he leaves undefined. In contrast to systems work, Dr. Kaplan states that "personality theory" offers little opportunity for prevention and little opportunity for clinical success

in the brief periods of intervention that devastating illness permits.

As I pursue this excursion, I need to explain that I'm not sure which personality theory Dr. Kaplan is referring to. But, having spent ten years at Stanford, Dr. Kaplan's home base, and recalling how mentioning the name "Freud" was enough to make grown men and women in their Department of Psychiatry do embarrassing things, I can guess which personality theory he means. So, as a committed clinical and academic psychoanalyst, I must now say something about Dr. Kaplan's spicy suggestions about personality theory, or psychoanalytic theory and practice. Later in the course of this discussion, I'll offer a few additional comments about the potential contributions of psychoanalysis to the treatment of children with catastrophic illnesses and to their families.

Personality theory, Dr. Kaplan says, calls for the long-term treatment of individual character in order to affect behavior. This is a condensed, and I believe blurred statement. As we all know, psychoanalysis as theory and psychoanalysis as a form of treatment are two different things. The unique character of psychoanalysis as a clinical modality has richly and extraordinarily contributed to our understanding of personality and its development. But, psychoanalytic personality theory, per se, has never operationalized the clinical practice of psychoanalysis. By contrast, there is an implicit theoretical matrix surrounding systems therapy, and I believe that this theory inevitably invades the systems therapist's clinical work. This is also a point that I will develop shortly.

For the moment, let us stay with psychoanalysis. It was Freud (1924) who maintained that any digression from classical psychoanalytic clinical treatment, which still recognizes the fundamental deeper meanings that psychoanalysis teaches us, (for example, transference and resistance), and takes these as the starting point of its clinical work, may call itself psychoanalysis, even though it arrives at clinical styles other than its own. Adherence to an understanding of "deeper meanings" has spurred the growing literature on psychoanalytically-oriented brief psychotherapy and crisis intervention (Malan, Sifneos, Aguillera and Messick, 1974).

The deeper functioning of the psyche is not dealt with by Dr. Kaplan in this paper, ostensibly because he regards such a concern as unnecessary and a waste of precious therapeutic time. But, I believe, there is a critical sense of the patient which becomes lost to the therapist if one bypasses this important attitude.

Let me amplify this issue. In his paper, Dr. Kaplan writes:

> "In short, our ability to resolve or mitigate the psychosocial problems associated with cancer is severely

> limited if we look solely to the individual and his/her personality for their resolution. The situation is comparable to the dilemma we would face if we sought to reduce traffic accidents by holding the driver responsible for them. The remedial activity possible under the theory of driver responsibility is limited to the selection of drivers and to training them in safe driving procedures."

Dr. Kaplan proceeds to elaborate how an ecological or systems approach to human behavior provides more comprehensive alternatives for the resolution of stress than does a focus on "bad drivers" alone. He asserts that an expanded focus on such things as the broad base of automotive safety features, the enforcement of traffic and speeding regulations, and the promotion of alternative means of transportation permits a more comprehensive evaluation of the stresses surrounding automotive and driver performance. In sum, a look toward the environment, in situations of stress, promotes a more thorough opportunity for meaningful intervention.

But, is such an environmental or systems approach always more comprehensive in its intervention strategy and in its understanding of stressed patients and their difficulties? If we keep our attention solely on Dr. Kaplan's "bad driver" paradigm, we may intuit that it is not.

Let me elaborate: A 35 year old physician is in analysis with me. Circumstantially, he has a morbid fear of cancer. He also has a horrible relationship with his wife, and, occasionally, with great guilt, picks up shapely prostitutes with whom he can engage in his private passion, anal intercourse. After such an episode early in the analysis, this physician reported the following dream: "I am driving my car. But, the license plate reads O M A. (This is strange because these are not his initials.) I am driving in the neighborhood where I usually pick up a hooker, when I suddenly see my wife on the sidewalk. She's there doing some shopping. I get real nervous when I see her, and step on the gas. I bolt up to the intersection in front of me. But the light is red, and I rear end the car in front of me. How could this happen?"

In his associations, the patient initially frets about the poor way that traffic lights are timed in this city. "Something should be done," he moaned, "to make the streets safe for people like me!" And, to give vent to Dr. Kaplan's argument, the patient is, in a way right. If our city kept its traffic lights in proper repair, it might improve the ecology for vehicular passage. But, as my patient began to search his soul further, he referred many times to his philandering as a sin. In short course, he saw that his car, his sin, and the license plate, O M A, contained all the elements of his dreaded psychic-somatic punishment, carcinoma. A

problem that started out as a manifest concern with traffic quickly became focused on its psychically more substantial elements, that is the location the patient's phallic automobile was headed: toward red lights and rear ends. Thus, not every traffic accident has a universal meaning, and processes of adaptation depend upon how the driver sees the event that has occurred. Despite Dr. Kaplan's ecological tenets, bad drivers, if they look deep to their responsibilities, have a thing or two to learn about their traffic accidents.

Now, my reason for belaboring the traffic accident metaphor is this: Any person's understanding of (and ultimate adaptation to) stress is exclusively predicated on his or her character--the amalgam of beliefs, thoughts, values, commitments and coping skills (Lazarus, 1978) that make us each humanly unique. Character, or personality, is hence something that we cannot bypass, as Dr. Kaplan would have us do. For character is the only vehicle through which we can understand the deeper meanings that physical illness has on a particular child, at a particular point in his life cycle, and the impact of that illness on his family and on its development. Adaptation to stress cannot be viewed as achievable through universal protocols, because the nuances of human psychological functioning demand a more individualized approach.

In our community, and I would venture to guess that in any community, a child's reaction to illness--even serious or life-threatening illness--varies as children vary. Young children, for example, if their home life is particularly poorly nurturing--with a poorly functioning ecological matrix, to borrow from Dr. Kaplan's patois--may find the process of hospitalization atypically unthreatening. Predictable age-specific responses, such as increases in separation anxiety, fears of bodily mutilation, and the like, become submerged in generalized low-key love affairs with the hospital and with the doctors and nurses who provide an affectively attentive and exciting alternative to the poor care usually found at home. Similarly, children from relatively large families, may when ill, find themselves the recipients of maternal caregiving experiences previously unknown in their lives. Both of these situations produce children for whom illness, even when catastrophic, yields such significant secondary gain that adaptation to it, rather than its eradication, is a personally perceived blessing. Helping such children understand that getting better demands their assistance is often a formidable task.

Alternatively, one can conceive of other situations where Dr. Kaplan's interventions might be more useful, but only circumstantially so. Adolescent boys, subjected to the ministrations of predominantly female nurses and the poking and prodding of primarily male doctors, have havoc raised with their normative developmental crises. Aggressive acting-out, as a byproduct of the enforced

passivity in hospital and general medical management, as a reaction to reactivated incestuous strivings, and as the outcome of exhorbitant castration anxiety, is the predictable rule of thumb. Parents, physicians, and mental health practitioners invariably have their hands full as they try to help such a young man understand that the treatment is good for--and necessary for--what ails him.

Parents of severely ill children have equally variable reactions, each requiring the finely tuned ear and the differential skills of the comprehensively trained psychotherapist. The emotionally well-functioning parent of a latency age child, suddenly struck with severe illness, may suffer the residua of partially repressed reactions reactivated under the influence of his or her child's psychological regression. Prior issues in parenting, such as a narcissistic failure to relinquish ownership of the child's body, may underscore some of the tugs-of-war between parent and child in this new, unexpected, and unfortunate caretaking situation.

Other narcissistic difficulties inevitably become manifest in some parents and these subject their ill children to severe feelings of rejection and abandonment. For a parent to face a threatened loss of a child, he or she must become involved once again with issues of omnipotence that the parenting process partially helps to renounce. For our individual senses of eternality or immortality (Erikson, 1978) are ensconced in our children. Our line, and hence, psychologically speaking, a piece of ourselves lives on in them. Catastrophic illness subjects that normative reaction to an ambiguous outcome. Parents may detach themselves from their ill progeny, as "offenders" to their immortal strivings. In our Division of Child and Adolescent Psychiatry, Dr. David Inwood and I have called the therapeutic aim with such parents "disidentification without detachment" from the ill child. Parenthetically, I learned, after Ivy's death, that the inability to disidentify without detaching was a significant problem for her mother. Such reactions are serious problems and most often defy solutions through Dr. Kaplan's protocol approaches to human behavior and adaptation.

Hence, as Anna Freud (1952) has pointed out, a therapist must attend to multiple characterological determinants in order to correctly assess the role of bodily illness in the mental lives of children and their families. The comprehensive therapist must understand the unique changes in a child's emotional climate as a product of the illness, specifically including, among other factors, the way a child experiences being nursed and nurtured, the way a child integrates restrictions in his movement and diet, and the way a child makes sense out of the amalgam of medical and surgical procedures to which he may be subjected. The therapist must know that physical pain and emotional anxiety are experienced differently by children at different developmental levels. Illness impacts on the distribution and balance between libido and aggression in a child and, in terms of

all of the foregoing, places significantly greater demands on a child's ego functions, particularly ego investments in defense and object relations.

I want to pause for a moment on this issue of changes in the defensive functioning and defensive organization of the ego under the impact of catasgrophic illness. In his paper, Dr. Kaplan repeatedly stresses that the seriously ill patient has difficulty adapting to the "reality" of his illness and that the therapist must help him do so. Resistances to such "reality," as these are manifested in such patients, must be dealt with and overcome. I question this approach, for it bypasses--or storms through--a patient's potentially self-protective ego functions. While a person's defenses must always be flexible, I doubt, in conditions of catastrophic illness, that they must always be pointed toward reality. As Lazarus (1978) states: "there may be many encounters in which little or even nothing can be done even when one has gotten all the available information about a problem. Under such conditions, living optimally or even adequately requires that we tolerate a high degree of ambiguity, or even that we engage in some self-deception (p. 32)."

He continues:

> "Two major functions of coping (defense) must therefore, be considered: First, to change the situation for the better if we can, either by changing one's own offending action...or by changing the demaging and threatening environment; and second, to manage the somatic and subjective components of stress-related emotions themselves, so that they do not get out of hand and do not damage or destroy morale and social functioning. These functions are sometimes...contradictory....For example, we make ourselves feel better in the face of harm or threat by palliative modes of coping, for example, by denying, intellectualizing...avoiding negative thoughts, or by taking drugs....These make us feel better although they do not change the actual person-environment relationship. Under certain conditions, when it doesn't countermand needed adaptive actions, this may help greatly (pp. 32-33)."

Hence, adaptation is not an invariant imperative, as Dr. Kaplan leads us to believe, but rather a process inherently enmeshed in a person's character. How much we want to help any patient with catastrophic illness adapt is intrinsically related to the deeper meaning that such adaptation will have for him or her. Under some circumstances of serious illness, it may do no harm to let patients or families believe what they want.

Finally, let me consider a basic issue in this paper, and the

one that I believe organizes Dr. Kaplan's thinking about the tasks of adaptation to serious illness. That issue is the implicit theory which underlies the clinical operations of the systems therapist. This therapist seems to believe that a family, as a biobehavioral system, develops a psychically homeostatic way of operating over time. The family's component members assume roles which contribute to the homeostasis of the system. The system's operation is optimally facilitating both its adaptation (to reality) and the psychic economy of its individual members. Stress, occurring within the system, or impinging upon the system from outside, disrupts the system's homeostasis. If the disrupted homeostasis also fosters maladaptive coping in the system's attempts to regain the lost equilibrium, then psychopathology results.

Let us look at this model more closely. If systemic homeostasis is disrupted, we could say, following the teachings of individual psychodynamics, that the "narcissistic balance" of the system is damaged, or "wounded", if you will. Like personal narcissistic insults, the narcissistic hurt inflicted on a system tends to depress its functioning. Thus, the externally perceived stress, like cancer, is viewed as a psychogenic toxin, against which, when it depresses its function, the system must first "grieve" and then "readapt." This is not to suggest that cancer is not a grievous event in any family. But it does suggest that the systems therapist sees cancer, as a stress, in accordance with the way he sees any stress. Thus he deals with it like any stress, and this is the fallacy in the systems therapist's logic. Stresses and processes of adaptation are not unique in every person nor in every family. I believe that I have demonstrated that in the course of my discussion. But all stresses and processes of adaptation are understood, by the systems therapist, in terms of a "common denominator." Hence, these notions become embedded in the "character" of the systems therapist, and they define his work.

Cancer in a child, the ultimate terror, is not only difficult for a child and his family to deal with, it is also difficult for any caring professional to witness. Each psychotherapist must find a way to cope with his role as helper to families managing their encounters with catastrophic illness--a gross illustration of what Sir Francis Bacon called the parental role as "hostage to fortune." But for any therapist to place adaptation to environmental reality before a patient's or family member's particular fears and pains, accessible only through knowing the individual character, is, it seems to me, to contradict Dr. Kaplan's stated goal. For if we do not offer to the dying and to those who love them the privilege of individual pain and its resolution, then we deny them the dignity which keeps us human when our hamanity is most threatened.

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CROSS-CULTURAL PERSPECTIVES TO CHILDHOOD CANCER

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A black mother, who is a member of the Holiness Church, begins praying and fasting around the crib of her infant child, who has suffered significant brain damage from a massive infection and has inflammation in the central nervous system. The mother refuses further tests to elucidate the nature of the brain damage and, instead she wants to take her child to her bishop, a family friend. The mother is noted as uncooperative and considered a fanatic in her religious beliefs. The mother is then evaluated by a court-appointed psychiatrist, who felt she was a "paranoid schizophrenic" and recommended that the baby's visits be supervised. The hospital staff held firmly that the child remain in the hospital, regardless of the wishes of the family (Redlener and Scott, 1979).

In an Arizona hospital, an Indian child is seriously ill and is visited by many relatives, some fifteen in number are in his hospital room. The relatives sit for long hours, never exchanging words. Talking is unnecessary; being there is important. What about the rule, "No more than two visitors at a time" or "Only immediate relatives allowed?" (Primeaux, 1977).

In Korea, a young wife is found to have a serious life threatening illness and approval must be obtained for hospitalization. The health practitioners must explain the problem to her parents-in-law, as they are the key figures of authority

within the family. The husband does not have the power to make this decision, nor does his wife (Foster, 1973).

These examples illustrate contrasting group and cultural approaches to health care. Failure to understand these differences can significantly determine the course of treatment with a seriously ill person. As we are dealing with a disease like childhood cancer which requires a treatment program over an extended period of time with states of remission, the need for this understanding is even more essential. The purpose of this paper is to examine some of these cultural differences in thinking, acting and believing in relation to the impact of cancer on the family.

INTRODUCTION

The following are premises about medicine which are critical in a cross-cultural approach: Medical practice can be conceptualized as a social system where the participants have defined roles and value sets. The behavior on either side of the therapeutic relationship derives in part from understanding the social role in that situation and the kind of behavior appropriate for it. Most importantly, medicine is a part of culture. What do we mean by culture? Culture has a variety of meanings, but most practically it is a guide for living and includes all the accumulated ways a group of people solves problems which are reflected in the people's language, dress, food, traditions, and customs. Culture functions as a guide to make life secure and enduring to the human species.

Saunders (1954) notes that medicine is considered a part of culture because it is comprised of a vast complex of knowledge, beliefs, techniques, roles, norms, values, ideologies, attitudes, customs, rituals and symbols which all combine to form a mutually reinforcing and supporting system. In our culture, persons who are trained in a particular professional discipline like medicine, nursing, social work, and psychology may be thought of as a subcultural group. When the practice of medicine involves the application of elements of the institution of medicine in one culture to the people of another, or from one subculture to members of another subculture within the same cultural group, the actions of the healers may not be fully understood by the patients. When the patients' responses do not meet the expectations of the healer, the relationship may be unsatisfactory to everyone concerned. To a large degree, these differences can be reduced when the healer is knowledgeable of his own culture and that of the patient, and willing and able to alter elements of his medicine so as to make them fit the expectations of the patients with whom he is working.

CULTURE OF THE HEALING PROFESSIONS

What are some of the shared attitudes, belief systems and knowledge of the healing professions in our society?

It is largely a culture that places a great premium on information and knowledge arrived at scientifically. Central to the cognitive system of the healers is the assumption that mastery over nature and control of illness are possible by the application of scientific methods and knowledge, which are believed to be effective in healing sick bodies. Friedson (1970) points out that healers feel that what we do, does good rather than harm, and that what we do, makes a difference between success and failure rather than no difference at all. Action is preferred, but action with very little chance for success is to be preferred over no action at all. One value that the physician learns during professional training is "the responsibility of the doctor for the welfare of the patient, the responsibility he/she has for the damage he may do to a patient if he performs badly and, conversely, for the good he can do if he performs properly (Becker and Geer, 1963, p. 172)." This may explain partly the phenomenon of malpractice suits when the healer poses himself as so correct and assured in what he does that he may invite legal action when he fails to deliver.

When it comes to serious and life-threatening disease, we place great value on large, complex, well endowed medical institutions as the best places for treatment. These institutions and hospitals are administratively marked by an efficiency and bureaucratic organization designed to provide high quality technical-scientific care to large numbers of patients. While this has few disadvantages to our scientific medical view, it is necessarily arranged with a degree of inflexibility which may limit the possibilities for dealing with patient expectations, desires, emotional or social problems (Redlener and Scott, 1979). We emphasize the multidiscipline health care team, composed of a variety of professionals priding themselves on a scientific approach. A great deal of value is placed on open and candid sharing what we know about illness and its treatment with the patient and family.

These are some of the overriding influences that shape our professional thinking and influence our understanding and approach to patients. Obviously, not all in the healing profession share these beliefs and values in the same measure. Certainly one has to be careful not to universalize what we hear, see and believe, but the above is being proposed as major components of the value and belief system shared by the healing professions in America.

RELIGIOUS INFLUENCE ON UNDERSTANDING DISEASE

Interestingly, a notable example of western civilization, an older country with a great deal of sophistication and culture, has a different attitude about cancer than prevails in America. Mme. Adonis (1978), an oncology nurse in a French hospital, writes that the vast majority of patients in France with cancer remain unaware of their diagnosis and do not ask to be told the truth. They want to remain in doubt, and to entertain the illusion that they may have some other disease. When the patient finds that he has cancer, he will often become completely unnerved and plunge into a state of moral distress. Adonis compares American and French attitudes: "The difference in attitudes towards cancer is due partly to the fact that the French are not as well informed as the American public about the advances in cancer therapy...due to complex cultural and religious reasons where cancer is seen not merely as a disease but as a punishment or the devil's curse, as it were" (Adonis, 1978, p. 112). Adonis further notes that with the exception of a few number of specialists, most French doctors and nurses have done little to change this situation, since they are part of the cultural attitude and have the same mystic dread of the disease. This may explain why the majority of physicians and surgeons in France rarely disclose the truth. And sometimes they never even recommend treatments which could in many ways improve the prognostic outlook because of their religious beliefs.

A similar attitude prevails in many Latin American and Asian countries where religion plays a major role in the life of the individual. People from these countries from all economic and social classes who have cancer, are rarely told of their condition; and, especially with children, the family protects the child from knowing the details of the illness.

The belief that illness is a punishment for wrong doing is widespread in human society. Where it occurs, the social order is often identified with the moral order of the universe. Illness being caused by misconduct may have been a very early form of social control in the development of human society. And perhaps the most important purpose of this indigenous concept of etiology is to provide sanction and support for moral and social symptoms. The idea of punitive sickness is, of course, no stranger to us and has been a feature of Judaic Christian beliefs concerning the consequence of sin.

Sigerist (1977) makes the point that in the Semitic culture there exists the attitude that the sick man is not an innocent victim but rather that he has deserved his suffering because of his wickedness. Sickness is punishment for sin. Sickness is given by the just God who is angry because of an outrage committed by the

afflicted person. This is the dominant judgement voice in the Old Testament. God is revealed as Law, whoever follows it piously will be blessed in this world, whoever breaks the law will be punished. Every disease is seen as punishment. Every suffering for sin maybe not only for the sins of the individual, himself, but for those of parents, for those of his relatives.

The Holiness religion, which is practiced among poor blacks and whites has the view that the Earth is a dangerous place where the individual is vulnerable to attack from the world of nature and from his fellow man. The individual is subject to punishment by his God. God can send illness as punishment. Feeling of helplessness engendered by such understanding is reflected in a dependency upon the supernatural.

What about children who have not lived that long to have sinned, committed a transgression, broken God's law? Among American Indians where the patient himself has not been guilty of any social or ritual misdemeaner, the lives of his parents and even grandparents will be explored. An etiology of this kind which states that others may suffer punishment for one's own transgressions fosters the value of social interdependence and provides a rationale for the afflicted child. Members of the Holiness Church see punishment being visited not only directly on the person who has sinned but, alternatively, upon a loved one such as a child. Biblical scripture is cited--Exodus 20:5 "for I the Lord thy God am a jealous God visiting the iniquity of the fathers upon the children unto the third and fourth generation of them that hate me." The Old Testament which is a basic document for many religions including Protestant, Catholic, and Judaism clearly influences the thinking and beliefs of many in our country and elsewhere.

TRYING TO COMPREHEND CANCER

The nature of childhood cancer lends itself to consider other than physical causes as the basis for the disease, to find something pernicious and evil. It can strike any part of the body. All areas of the body are vulnerable. Other major life-threatening illnesses like diabetes, renal disease, and hemophilia are specific to one area or system of the body. Cancer strikes at random and all over the body. The etiology of many childhood cancers is unknown. In contrast to children, adults with cancer can sometimes make sense of their cancer by pointing a finger at smoking, not eating sufficient fibrous food, occupational hazards such as working with asbestos or being exposed to radiation. In adults, there is often a buildup of the cancer over an extended period of time. The adult has lived, experienced, has had some years on this earth; with children it's more poignant, as their time on earth has been painfully shortened. The child cannot fight back like adults, and

unlike adults, they have had little experience in fighting life's battles!

Childhood cancer strikes at the heart of the family because the next generation is eliminated. The death of a child represents a dreadful reversal of the human life cycle. With children, cancer strikes with audacity, daring and suddenness. A parent will ask: How can it be? My child didn't smoke, didn't work in an asbestos factory, and possibly didn't have more then one or two chest x-rays? Comaroff and Maguire (1981) in a study of parents who have children with leukemia found the parents reviewing their own biographies, passing from questions: "Should I have breast fed? Could one x-ray in pregnancy have done it? Could it be that I work with chemicals? Perhaps it's because we lived in such a filthy industrial environment?" Some of the parents tentatively invoked metaphysical explanations. This lack of any rational explanation may understandably compel some parents to look to religion. "Maybe I did something wrong? Maybe God has punished me? It is a punishment for something we have done." Those who hold strong beliefs in divine causations were less concerned with other aspects of etiology.

All cultures provide repertoires of explanation and theories to account for and manage such events. Comaroff and Maguire (1981) write "Western industrial societies have come to think increasingly in the idiom of scientific explanation in which objective and neutral principles serve to order the elements of a materially constituted world." These theories are impersonal and amoral, and do not relate specific physical causes to more embracing social, moral, or spiritual orders. Scientific explanations fail to account for the seeming random occurrence of a wide range of "natural events" such as the onset of disease. However, where such afflictions strike at the heart of everyday realities and resist control, it leads to questioning tacit assumptions about reality and the nature of human control. And it is in such cases of which childhood cancer is typical that the ambiguities of current biomedical knowledge are most keenly perceived.

In our society, books, movies, television programs and newspaper stories about cancer are readily available to the public. We are mystified, baffled, frightened and overwhelmed to deal with our feelings, and yet we insist on reading, viewing and sharing personal accounts. The stories rarely ever have a happy ending. Obviously, as a culture we have a great deal of difficulty dealing with it. We are too stunned and frightened. By the victims and their survivors sharing their accounts, it affords a release for us. Possibly, by vicariously sharing it, we can experience it and thereby avoid it.

FAMILY AND THE HOSPITAL

As a society, we rely on the hospital as the primary physical institution to provide care for patients with serious illness. However, within the past several years, we are beginning to consider again the patient's home as a place to provide medical care. Dr. Martinson's (1978) paper on home treatment is a beginning recognition of the potential of the home as a place to care for the terminally ill child.

This emphasis upon the hospital and the large medical institution often leads to a separation between the family of the patient and the professional health care family. Generally speaking, there is not an effective integration of the patient family unit in the hospital. Often staff assume an adversary position towards the family. No doubt in dealing with the child-patient we tend to involve the family much more. Shapiro (1980) suggests that with the ill child, a total shift in emphasis occurs so that sometimes the patient is ignored and the focus is exclusively on the family.

In a review of studies of family support networks, Pilisuk and Froland (1978) found that the loss or absence of familiar networks of social support have been linked to coronary disease, disorders of pregnancy, school truancy and recovery from certain types of cancer. Shapiro (1980) cites cross-cultural evidence that in a moderately well-adjusted family, the presence of family members in patient care exerts a positive influence on health.

This separation of the natural and professional health care family may derive from our emphasis on a more scientific approach to care, that hospital based professionals who have access to this kind of knowledge are in a much better position to care for the person. It is this attitude which may place us in difficulty with other cultural groups who believe much more strongly in the role of the family.

FAMILY AND THE CULTURAL MILIEU

In order to understand how the cultural milieu affects the family's responses to the child with cancer, it is critical to view the child within the context of the family. The family, accordingly, is then influenced by being a member of an ethnic or minority group, with certain culturally prescribed beliefs and behaviors unique to that group which bear on how that child and family behave and respond to the diagnosis and the treatment process. These factors must be constantly kept in mind because as a result of recent treatment advances, cancer is an illness that will often require treatment over a long period of time. Some of this treatment may take place in the hospital and a good deal of it will take place outside the hospital when the child resides in the

community. How that child and family respond to these extensive and long term treatment programs will in many respects be influenced by their cultural groups. Above all, the tendency to look at the child in a restricted patient centered perspective must be resisted.

The perspective needs to include how children are generally valued and viewed within the society. Within the past hundred years in this country, the size of the family has decreased largely because we have moved from being an agricultural country to an industrialized one. In an agricultural society, a large number of children are necessary in order to carry out many of the functions of an agrarian economy. In contrast, an industrial society uses a much smaller labor force. With more time available to pursue one's own interest, large numbers of children in a family can be viewed as an economical liability and, certainly, in this day and age of inflation, the cost of caring for and educating a child is exhorbitant. However, children are generally viewed positively and, as a rule, we tend to want to prolong the life of children when they are afflicted with any serious illness.

Liebow's (1967) interviews with lower income black men found that they viewed children as liabilities, primarily economic liabilities. Liebow found a consensus that children "will snatch a lot of biscuits off the table" (Liebow, 1967, p. 92), the more children, the greater the liability. Children are also viewed as liabilities in relation to the important realm of man/woman relationships, because children deter secrecy and limit freedom of action. A child from this type of milieu with a diagnosis of cancer might be viewed differently than a child from a group who believes that children are assets rather than liabilities. However, one has to be careful in making these generalizations about how different cultural groups value a child. Generalizations when applied across all cultural groups, ignoring subcultural factors and the particular family, can lead to oversimplified generalizations and be quite destructive.

The particular sex roles assumed by males and famales in certain groups affect how people respond to a cancer diagnosis. For example, Spanish and Mexican American men who place a great deal of value on the machismo personality may outwardly act quite indifferent to a child's cancer diagnosis in contrast with the parent who is not machismo oriented. These fathers often display close ties to the children within the confines of their families and ethnic groups, but not publicly among strangers. Possibly, if the child is male, and, depending upon his age he, too, may be in the throes of developing a machismo personality. Therefore, the outward reaction to the diagnosis will be influenced and patterned by these cultural characteristics. In contrast, where women in Spanish and American families have the position in the family of

being both the religious and moral leader, the health professional needs to work through these women to facilitate the families' understanding and eventual acceptance of the cancer diagnosis and the members' grieving processes.

In families of a female based household where the father is either absent from the household, or minimally present, and where the women may be engaged in a pattern of serial monogamy, health professionals may find themselves relating only to the mother of the sick child, one or more female relatives and any number of the mother's male companions. This is in contrast to the stereotypical American nuclear family constellation where the father may have a more major parenting role. Health professionals may become frustrated in these situations as they attempt to assess the impact of a cancer diagnosis upon the child and his family because of "the need to identify and maintain meaningful interaction and communication with transient family members which makes the rendering of effective health care complicated and difficult" (Clausen, 1978, p. 398). Clearly, one has to be attuned to the nature of the family structure because individuals whom we may think are significant in one type of family structure may not be so in other families.

Interestingly, in American Indian families, children learn the importance of the tribe and the family. The real poverty to Indians is to be without relatives. When a child is ill, it is important for the family members to be present in the hospital to offer care and concern. The relatives may merely sit close to the patient, for talking is not necessary. Sometimes a whole group of Indians, twelve or more Indians, may even choose to camp on the hospital grounds in the event they have travelled a distance. Questions may be asked, like how realistic are such rules that there be no more than two visitors at a time, or only immediate relatives be allowed when faced with this response of the extended family structure? One must be very cautious in these cases when relatives do not leave, that they are not labeled by health professionals as uncooperative. Primeaux (1977), a nurse and Cherokee Indian, writes that an Indian child may have more than two sets of grandparents and other relatives depending upon the kinship patterns of his or her tribe. In some tribes, first cousins are treated as brothers and sisters. Indian grandmothers play an important role in the care for children, for often it is the grandmother who is the permission granting agent for procedures and care rendered during a child's hospitalization. A somewhat similar family structure exists with many Spanish and Mexican families where each child in the family has a set of godparents who in all aspects of childrearing act as co-parents with the parents, and the child may have very strong and vital feelings towards these godparents as well as towards his biological parents.

RELIGION AND HEALTH PRACTICES

As previously indicated, religious thought can influence how individuals understand the etiology of physical disease which doubtless bears on approaches to treat disease. In the American Indian family, there is very little distinction between medicine and religion. Illness is viewed as the imbalance between health and religion, because health is viewed as the perfect balance between the Indian and his environment. In these cases, health can only be restored through acts of his fellow men, primarily the "medicine man." Primeaux (1977) describes the religious ritual where the Indian grandmother might sprinkle cornmeal around an ill child's bed. In some tribal cultures, there are sacred foods. For some tribes, corn is sacred, and cornmeal is used in a variety of curative ceremonies. One might ask how long the cornmeal should be left on the floor? This is not as important as how free the family feels to do this, and the respect shown for this activity.

Religion is also a central focus for Spanish and Mexican families and the Curandero, a person knowledgeable about healing and curing, will often be involved in the treatment of the patient, and might be initially consulted in time of illness. In families like this, once sickness occurs, like a child with cancer, the family will often seek consultation and medication from within the group and then from members and other people in their network. Finally, the family will turn to a Curandero, and where this doesn't work, then will go to a nurse or doctor. Clearly, this procedure may delay treatment of the disease where time is of the essence. These two health belief systems may be at odds with one another, but each is believed to be the correct way by members of both systems.

In the Holiness Church, there is the basic conviction that God controls healing and only those who possess "the power" to heal are believed to be able to effect a cure. No one (and this includes medical doctors) can acquire this power without perfect faith in God and His ability to restore health. In varying degrees, some Church members believe that doctors and their medicines cannot heal. The parent, who is a member of the Holiness Church with a seriously ill child may want to take the child to a minister of the Church. Rather than denying and belittling this desire on the part of the parent, it would be beneficial for the patient and for the health professional to involve the minister in the interests of the patient as a whole person.

VERBAL AND NONVERBAL COMMUNICATION: CULTURAL PERSPECTIVES

This discussion of culture and health belief systems would be incomplete without a consideration of cultural factors in the prag-

matics of everyday human encounters. Language and communication patterns influence how parents respond and interact with health professionals. Careful attention has to be paid to both verbal and nonverbal cues of communication, involving the use of facial and body expressions or distancing mechanisms. American Blacks have features of their speech which separate them from Anglo and others due to their historical development. An urban black child may be thought to be verbally deprived, but in studying their language one finds the opposite to be true; that the language is extensive and does communicate adequately what they are thinking and feeling (Clausen, 1978).

Eye contact may be very significant too. For example, a Puerto Rican child will avoid direct eye contact with people in authority. In addressing a Puerto Rican child, the avoidance of eye contact should not be taken as an unusual pattern, whereas in Anglo families, eye contact is usually directed to the person to whom one is speaking, and it means paying attention. This pattern of avoiding eye contact is also seen with the American Indian because to look directly into another person's eyes is an invasion of that individual's private soul and may even take the soul away. Downcast eyes are not due to shyness, but may be a culturally determined way of realting to people.

Interestingly too, even a strong handshake, which is characteristic of strong personalities among members of the Anglo culture, is seen as an aggressive act by many Indians. In fact, an Indian may withdraw slightly from a person with a firm handshake. Also, the actual physical distance in a social relationship has to be considered. Anglo people often will maintain a foot or so of distance when talking to each other; whereas in Latin cultures, the actual physical distance is much less. This actual physical distance can be interpreted by others as aggressive or evoke sexual behavior. Indeed, it is not, because it reflects their view of how people should relate to each other.

SUMMARY AND CONCLUSIONS

The healing arts are clearly a social activity and largely depend on the course of the relationship which is determined by the knowledge, skills, feelings and attitudes of the professional practitioner, as well as that of the patient, his relatives and friends which stem from membership in and identification with cultural and subcultural groups. Both patient and practitioner have sets of values which establish limits to what each can and will do in the relationship. These variables will influence the course of the patient-practitioner relationship.

Where the knowledge, attitudes and behavior are largely com-

plementary and mutually reinforcing, the relationship and its outcome may be highly satisfactory to everyone. When the practitioner and patient have roughly the same concept of the disease, its cause and treatment, and if the patient is confident in the skill of the practitioner, and in the practitioner's interest in him, and the practitioner likes the patient and feels assured of his trust and cooperation, then the relationship may be satisfactory for both. Where this doesn't exist and the patient mistrusts, the practitioner is ignorant of, has hostility towards, and lacks respect for the patient's viewpoint, then neither is likely to benefit optimally from the relationship.

Some hospitals and health care teams which find it too difficult to adopt a transcultural view on their own have an additional team member who is a "culture broker", usually a medical anthropologist, well informed in the area of the beliefs and practices of the various patient populations. The culture broker acts as a bridging person who negotiates between different cultural traditions. Short of utilizing a culture broker, Saunders (1954, pp. 215-225) offers a number of valuable suggestions for working with any cultural group in any geographic setting which are contained in the following summary:

1. We need to resist the temptation to equate cultural differences in behavior with ignorance or lack of understanding. People may not know the same things we do, but they may have some understanding of disease and its treatment, and what needs to be done, though different from ours.

2. We need to be alert to the person's uneasiness, anxiety and/or fear in the medical situation. Individuals unfamiliar with institutional routine and the high degree of professional specialization cannot understand why all aspects of the problem cannot be handled by one person may feel that no one is interested in them and taking care of their needs. We would all agree that this can easily take place within our large medical complexes.

3. Wherever possible, there should be available staff who can speak the same language as the patient. Otherwise, speak in very plain and simple language and raising the voice beyond the volume required for normal conversation does not bridge the gap in communication.

4. Understand the folk medical beliefs of the group you are working with so as to know when your notions differ importantly from the group.

Above all, we need to develop respect, sensitivity and flexibility in approaching patients from other cultural groups and to

be mindful of the assumption and notions that guide and influence our and their behavior.

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The Bible

IMPORTANCE OF CULTURAL AND RELIGIOUS EXPERIENCE: DISCUSSION OF DR. FLOMENHAFT'S PAPER

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Dr. Flomenhaft's paper began with vivid illustrations that made the point: Contrast in group and cultural approaches to health care holds not only for persons of dissimilar cultures but within each culture. I will use my experience in Taiwan to relate to the paper. In Taiwan, it was very evident to us that the nurses and nursing faculty were not aware of some of the most common sentiments and practices of persons in their own culture. Perhaps this represents subcultural differences, because the nurses were well educated, while many patients and families were not. Some things that these nurses were not fully aware about the patients included:

(1) extensive use of fortune tellers

(2) expensive financial expense for religious practices such as paying for vows and seeking services of ritual specialists

(3) the extent to which grandparents influenced family decisions, sometimes disastrously. For example, the grandfather who refused to have a child operated upon until too late, and only then did so when a fortune teller indicated to his satisfaction that "out of evil good will come."

(4) the extent to which the nurses were unaware of how much pain the children suffered because the parents did not volunteer information.

When the patient and the practitioner agree on the seriousness of the disease and the necessity of doing certain things, the re-

lationship is effective. For example, I thought of the confidence many Chinese families had in the herbal medicine, and would often add herbal medicine to Western treatments.

The cultural values of the scientific medical tradition are richly stated. Because of the distance between popular ideas and medical tradition in Taiwan, there was often delay in seeking appropriate help. We tend to accept large and complex medical institutions as the best place for treatment. This raises serious financial issues for a country like Taiwan because of the cost of placing a sophisticated system on a society that originally was more rural and is not yet able to sustain such a system economically and presently lacks the social infra-structure to make health care equally available to all. Quality and technology raise the serious question about the general availability of medical care to deal with both acute and protracted illness.

I was in France myself at the American Hospital, and the speaker's section on France could be challenged. The rationale for "Mystic dread of disease" is hardly peculiar to France and seems inadequate to account for the cultural difference. Being poorly informed is no doubt a part of it. One also wonders if this lack of communication is something that has been cultivated by the profession, and that people actually know or guess much more than the doctor is ever aware of. Certainly, Japan is a case in point, as well as for many of the children in Taiwan. Professionals may be fully as much to blame for lack of patient information as patient perception. Dr. Flomenhaft pointed out correctly that especially children are not told, but does this mean that the child does not know? What about the Chinese boy who kept a diary, or the girl from a Christian family who visited other children in wards with cancer and sought to comfort them? Yet other Chinese parents even tried to hide death of a child from their other children by the following statements: "He's gone with someone to America." "Weren't you mean to him?" Or, "He's too far away to come back now."

I would challenge Siegerist's material that sickness is a punishment for sin. The paragraph on God was very one-sided. The picture given of God as a tyrant is inadequate. In fact, in the Old Testament this idea of suffering was early transcended. Many of the Psalms, much in Prophets, and the whole book of Job are devoted to problems of righteous suffering. Separating suffering from etiology did not lessen the pain of sickness, but even intensified it. In Taiwan, Karma was one of several etiologies given for sickness-misdeeds of past life that caused this. I recall the family in which two boys had hepatoma. The older boy was said to be an "imposter" who was oppressing the younger brother, perhaps gaining revenge for deeds of a past life. If the older boy died, then the younger brother had a chance. Ancestral tradition provides

an etiology. For instance, a paternal uncle who died in infancy was in two cases blamed for this. The solution was to provide sacrifice to the unattended spirits. The following story was given as an explanation for the death of a five year old child: There was the Taoist belief about death, that a God had descended for five years to view life on earth. When he died, he was worshipped as a God and a huge funeral celebration was done.

Our experiences with Chinese parents revealed that they sought to prove all kinds of things from experiences in the past: What had they fed the child as an infant? What are the child's food cravings? Did the mother have x-rays during pregnancy? I agree with Dr. Flomenhaft, "All cultures provide repertoires of explanation and theories to explain the random occurrance of the disease."

I am curious to read Shapiro's study on hospital as noted by the speaker which ignores the patient and focuses exclusively on the family. That is unique. Is that really so? By and large, it seemed that the nuclear family situation was the most flexible and the extended family often multiplied the problems. Also, in Taiwan, the maternal mother was a most significant figure of support in the early stages of the illness. The paternal mother was more important at death and post-death. Interestingly, for children who are hospitalized, the father spent considerable time in the hospital and the impact on his work is indeed significant. The role of the religious specialist in the healing process is very important where there is religious commitment. Medical practice should encourage and strengthen this rather than deter it. Physical healing and emotional healing cannot be separated from any of us.

Finally, let me speak to Dr. Flomenhaft's closing suggestion. We need to evaluate carefully differences in behavior stemming from ignorance or lack of understanding. I do wish to give an incident that occurred when I was in Taiwan: A young boy diagnosed with leukemia responded to treatment, had an excellent remission and went home on medications. Three months later, the mother brought the boy back. Metastases had occurred, and the symptoms were worse than before. What had happened? The mother had been so impressed with the response to the treatment and the optimism of the staff, that when the expensive medication ran out at home, she did not realize how essential those medications were to continue the remission.

The movement to a primary provider for each patient and family in a complex institution would be a forward step where the primary provider receives assistance and back-up from the rich resources we have in our medical complexes.

Language skills are critical and I was fortunate in Taiwan that the staff members conducted the interviews in the language of the

interviewee. In reflection, especially here in our own country, we need to find out the folk medicine beliefs and identify the actual practices in a nonthreatening manner, so that when we wish to examine drug compliance with these practices, we have the data. Dr. Flomenhaft's paper on cross-cultural perspectives on childhood cancer is an important paper. In many parts of the U.S. various cultural groups are in existence. We certainly do need to become more flexible. Your paper will serve us all well.

HOME CARE FOR THE CHILD WITH CANCER[1]

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The purpose of our study, "Home Care for the Child with Cancer", was to examine the feasibility and desirability of a home care alternative to hospitalization for children dying of cancer. Home care was defined as "the delivery of services, nurse-directed with physicians and other health care professionals as consultants, to enable parents to give comfort and care as required by a child at the end stage of life."

A pilot study was done from 1972 to 1975 in which home care was offered to eight families. In five families, the child did die at home. Based on this nonfunded pilot study, a federal grant proposal was submitted to the National Cancer Institute, Department of Health, Education and Welfare, and the project was funded in 1976. There were two research phases during the four years of the study. For the first two years, the grant provided staff who directed the nursing care of children with cancer at the end stage of life. During this time, collaborative arrangements were being developed with public health nursing and three hospital/clinic-based institutions. The grant staff organized and provided the actual care, and collected data on this care. During the third year, the coordination of the care, both directly and indirectly, was essentially turned over to three already existing health care organizations and to the public health nurses utilized by these institutions. In the fourth year, the grant staff then devoted their full attention to the question of the desirability of home care, and to the observation of what was happening in the three institutions. This was done to

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help answer questions regarding the feasibility of the institutionalization of this home care alternative.

The criteria for referral of terminal cancer patients to the study included the following: (1) the patient was 17 years of age or younger; (2) the patient had some form of cancer and was expected to die fairly soon as a consequence; and, (3) no procedures requiring inpatient hospitalization were planned. Whether the child met both the second and the third criteria were determined by the child's pediatric oncologist.

The services available for the family were as follows:

1. The nurse would be on call 24 hours a day, seven days a week.

2. The nurse would be available to help the family members, who were the primary care givers dealing with problems that might arise.

3. The nurse was available to make home visits whenever and wherever the family desired such contact.

4. The option of the child returning to the hospital was always open.

5. The child's physician could be called at any time.

During the first two years, 64 children were referred to the project: of those, 58 died. Sources of referrals for these 58 children were as follows: More than 50% were from the University of Minnesota; St. Louis Park Medical Center in Surburban Minneapolis provided the next largest number; and 15 children were referred from eight other hospitals. A total of 23 physicians were involved: Fourteen from the University of Minnesota, two from pediatric oncologists at St. Louis Park Medical Center, and, seven other physicians representing eight other hospitals.

The places of death for the 58 children were as follows: Forty-six (79%) at home, twelve (21%) in the hospital, with one of these children dying in a hospital in Mexico, and one child dying in an ambulance while returning to the hospital.

The range of ages of the children who died at home was one month to 17 years, with the largest number (13) being in the age range of 15 to 17. The ages of children with cancer who died in the hospital ranged from 3 to 17 years. The data suggests that the age of the child is not a significant factor in determining the feasibility of home care.

The period of time from diagnosis to death for the children with cancer ranged from less than three months to over nine years. The length of home care to death varied: Fifteen families were involved with home care for less than one week; four families, 1-2 weeks; seven families, 3-4 weeks; sixteen families, 1-3 months; and four families, over 3 months.

The direct professional nurse involvement for the 46 children who died at home was an average of 13.8 home visits, with a range from 1 to 110. The total number of professional nurse home visits for the 46 families, who had a child die at home, was 634 visits. A nurse spent a mean of 31.5 hours per family (range of 1 to 305.6). This home contact was supplemented by telephone calls. These ranged from one family who made no phone calls to the nurse, to another family who made 101. The mean number of calls per family was 22.7. Duration of telephone time during home care averaged 4.1 hours per family, with a range from 1 to 23.5.

Families who participated in our project resided in both urban and rural areas throughout Minnesota, North Dakota, and Wisconsin. Using the Hollingshead Two-Factor Index of Social Position (Hollingshead, 1958), we classified the families of the children who died at home from highest through lowest category 1-5, respectively. Forty-eight percent were the two lowest categories, while 22% were in the two highest categories.

There were 107 siblings in the families of the 46 children who died at home. Seventeen were between one and five years of age, the largest number of siblings were between the ages of six and ten years of age. In five families, the dying child was the only child; in another five, there were nine siblings in the family.

Parental status is also of interest. Fifty-four families were two-parent families and in four there was only one parent in the home. Three of these families were mother-only, and one was a father-only family. In the four single parent families, three of the children died at home, including the one headed by the father.

The place of death in the home for 31 of the 46 children was in the living/family room, essentially the center of family activity. The majority of the children wanted to be involved by seeing and hearing what other family members were doing. These children wanted to be near the family.

There were 58 nurses who worked with the families: twenty-four were hospital based; twenty-two were involved in public health nursing agencies; two were nurses on the grant staff; five were unemployed; and five were in related areas such as school nursing. We looked at the number of families cared for by these nurses and found that 13 families were assisted by a hospital nurse, either

from the referring institution or from a local hospital. Eighteen of the families were assisted by a public health nurse, six by the home care staff nurses, seven by unemployed nurses, and four by other nurses.

A few of the families had two co-primary nurses; three families had two hospital nurses; one had two public health nurses; and six had a combination of a hospital nurse and a public health nurse. We noted that less consultation with the project staff was required with the combination hospital nurse and public health nurse team. The hospital nurse was able to handle the emergency-type questions, and the public health nurse was able to handle situations requiring knowledge of local resources. An interesting observation that has evolved from this is the need for more nurses to "nurse-network'.

The age of the home care primary nurses ranged from 23 to 63 years. The experience ranged from one to 44 years since they had become registered nurses (RNs). Seven of the nurses had Master's degrees, 29 were baccalaureate nurses, four were nonregistered nurses, and the balance had hospital diplomas. The four nonregistered nurses included three licensed practical nurses and one student nurse.

The number of physician home visits through the time of death and immediately after the death of the child for the 58 families were as follows: Forty-four of the families did not have a physician visit at home, nine of the families had one physician visit; one family had two physician visits; two families had four physician visits; and one family had 17 home visits, including twelve visits by a psychiatrist.

Home visits by other health care professionals for the 58 families included; a laboratory technician who made one visit to three families and two visits to one family, an X-ray technician who made a visit to one family, an occupational/recreational therapist who made one visit to one family, a chiropractor who made seven visits to one family, a Home Health Aide who made one visit to one family and 43 to another, and a homemaker who visited one family 16 times.

Although no social worker made a home visit during the time of home care, data indicates social work involvement before referral to the home care project as well as with family following the death of the child. The reason for no home visit by social workers during home care was that the families who were involved with a social worker lived away from the medical center, and there were no social workers available locally.

With regard to the cost effectiveness of home care, we looked at cost figures as requested by insurance companies. For 46

children who died at home and on whom we had data, the duration of final care days at home was a mean of 38.9 days with a cost estimate of $1,218, a median of 20.5 days with a cost estimate of $705. This cost estimate is based on the cost of nursing services at the rate of $10. a day to be on call 24 hours a day and for telephone consultation, $45. per home visit, and $10. for a clinic visit. In discussions with insurance companies, they urged us to use a comparison group. The first group we utilized was a group of 22 children who had died at the University of Minnesota Hospital prior to 1976 and before our project was funded. The 22 children who died of cancer at the University of Minnesota Hospital had a mean duration of final care of 29.4 days, with a cost estimate of $5,880. based on the cost of nursing service and room and board at the rate of $200. per day. The median was 21.5 days, with a cost estimate of $4,300.

We have recently updated these cost figures. We have estimated a daily cost of home care per child at $51.79 which includes $40.04 per day for nursing care, based on $35. for the first hour of a visit and $10. for each additional half hour; $3.57 for room furnishings; $3.49 for equipment; $2.99 for supplies; $2.54 for medications; and, laboratory tests accounted for $0.14 per day. No cost was included for room and board because the family provided this. Constrasting the cost per day for a child who died in the hospital while receiving comfort care only was $279.91. This included $158.09 for nursing care, room, and board; $27.69 for supplies and equipment; $12.94 for medications; and, $81.19 for laboratory tests. The hospital based costs are thus about five times more than the home based costs.

The approach to assessing the results of home care have been guided by considerations of feasibility and desirability. Feasibility and desirability are not easily separated. Before something can be adjudged "desirable", it must first be demonstrably feasible. In that sense, both desirability and feasibility can be thought of as lying on the same continuum, with feasibility at a lower or more basic level, and desirability at a higher level. Thus, some "threshold" level of feasibility must be achieved before an assessment of desirability can take place. For some distance along the continuum immediately after this threshold level, it is very difficult to distinguish between desirability and feasibility. In a pure sense, the process is feasible. However, if that process is much more costly (in monetary or other terms) than existing alternatives, some would argue that the process is not feasible while others would couch that argument in terms of (non)desirability. If there are no immediate and obvious concerns about its "feasibility", the assessment can move to a higher level where an assessment of the desirability of the process becomes the focus.

The second consideration derives from the need to operationa-

lize the distinction discussed above. Because the process of home care was at a very early stage of development at the beginning of the project, the first concern was to demonstrate the feasibility of the process at the basic threshold level. We believe the study has demonstrated the basic feasibility beyond debate. The next level of assessment is the focus of the second part of this paper.

The effort in this area has been directed to determining whether or not there are important negative consequences to home care for the family, the professionals or others involved in the care of the dying child. Because the project has been concerned with developing the home care model in practice and with assessing these basic levels of feasibility and desirability, the study design had not included statistically relevant control groups or random assignment of cases to various levels of care. Rather, the approach has been one of ruling out negative consequences of home care. At a somewhat higher level on the feasibility-desirability continuum, basic positive consequences of home care are also discussed. However, questions related to the highest order of desirability, particularly in contrast to other modes of care, remain to be answered in other study designs.

The intent of Phase One of the project was to develop and put into practice a model for home care of children dying of cancer. In Phase Two, the intent was to move the provision of that care from the research project to the community, to institutionalize home care in existing health care delivery organizations.

Place of Death

The first result of home care is the place of the child's death. Because home care was intended to permit families to care for their children at home through death, the proportion of children who received home care but died in hospital could be an indicator of the degree to which the model worked. In Phase One, 12 (20%) of the 58 children who received home care died in hospital or en route to hospital; four (22%) of the 18 Phase two children died in hospital. Thus, about one-fifth of the children who entered home care returned to a hospital to die. The following sections discuss the differences between home care cases where the child died at home and those in which the child died in hospital.

Differences in Personal and Family Characteristics

There were no differences between Phase One families whose children died at home and those whose children died in hospital in terms of religion, family size, socioeconomic status, rural-urban residence, gender of child, or child's order of birth in the family. In sum, there is no relationship between place of death and any of

the personal and family characteristics measured.

Differences in Diagnoses and Physical Condition of Children

Table I shows that there are few differences in diagnoses between children who died at home and those who died in hospital. The only diagnosis where there are more hospital deaths is the lymphoma category. However, since there are only very few cases involved, no significance test could be done.

Table I

Diagnoses of 58 Children who Received Home Care and Died During Phase One Home Death versus Hospital Death

	Children who Died at Home		Children who Died at Hospital	
Diagnosis	Number	Percent	Number	Percent
Leukemia				
ALL	8	17.4	4	33.3
AML	6	13.0	1	8.3
Other	5	10.9	0	-
Lymphoma				
Burkitts	3	6.5	0	-
Undiffer.	1	2.2	1	8.3
Histiocytic	0	-	1	8.3
Hodgkins	0	-	1	8.3
Neuroblastoma	4	8.7	1	8.3
Central Nervous System				
Medulloblas.	2	4.3	1	8.3
Astrocytoma	3	6.5	1	8.3
Brain stem glioma	2	4.3	0	-
Bone				
Ewings sarcoma	4	8.7	0	-
Osteogenic sarcoma	2	4.3	0	-
Other				
Ependymoma	2	4.3	0	-
Malignant histiocytosis	1	2.2	0	-
Malignant teratoma	1	2.2	0	-
Embryonal cell carcinoma	1	2.2	0	-
Rhabdomyosarcoma	1	2.2	0	-
Hepatoblastoma	0	-	1	8.3
Total	46	100.0	12	100.0

Table II

Comparison of: Physical Symptoms of Children who Received Home Care and Died during Phase One with Children Dying in the Hospital

Symptom	Children who Died at Home		Children who Died at Hospital	
	Number	*Percent (of 46)	Number	*Percent (of 12)
Difficulty breathing	32	69.6	4	33.3
Difficulty drinking	32	69.6	4	33.3
Difficulty eating	35	76.1	1	8.3
Bleeding	20	43.5	4	33.3
Mild	(5)	(10.9)	(0)	
Moderate	(13)	(28.3)	(3)	(25.0)
Severe	(2)	(4.3)	(1)	(8.3)
Vomiting	19	41.3	4	33.3
Seizures	13	28.3	2	16.7
Tumors, external	11	23.9	0	-
Decubitus ulcers	7	15.2	1	8.3
Diarrhea	7	15.2	1	8.3
Abscess	4	8.7	2	16.7

*Children generally had more than one symptom, hence the percent will total more than 100.

Beyond the global designation of the child's diagnosis, one could anticipate that there may be certain aspects of the child's physical condition that would make hospital readmission more likely. However, Table II shows that only two of the 12 recorded symptoms occurred with a greater proportion among children who died in hospital than among those who died at home--severe bleeding and abcesses occurred with a somewhat higher proportion among home care children who died in hospital. While these occurrences involved a total of only three children, in each case interviews with the parents indicated that the occurrences of the symptom was highly related to the parents' decision to return the child to hospital where the children subsequently died. It should be noted, however, that in two of these three instances, there was parental dis-

satisfaction with nursing care. However, these same symptoms also occurred in home care children who were not readmitted and who remained at home through death. Thus, while some families were more comfortable in re-hospitalizing children with abscesses or severe bleeding, others chose to keep children with those symptoms at home. There is, therefore, no evidence to suggest that home care is necessarily inappropriate for children with certain symptoms. On the other hand, it is probable that the occurrence of certain symptoms in the absence of immediate support may lead some parents to readmit their dying child to the hospital.

Differences in the physical condition of children receiving home care were assessed at the time of admission to home care, at one week prior to death, and at six hours prior to death. These periods were chosen to provide an overall description of the children as well as a vehicle for comparison of nursing services required and the difficulties encountered by parents.

Information describing the physical condition of each child was abstracted for the three selected periods. While some nurses gave less complete descriptions than others, and the time periods in question were not always observed because of the short duration of home care, descriptions of physical condition at time of admission

Table III

Ratings of Physical Conditions of 46 Children who Died at Home During Phase One of Home Care

	Admission	One Week Prior to Death	One Week Prior to Death
Total number of children	46	46	46
Total with complete information	45	30	46
Total with agreement of at least two raters	45 100% of 45	30 100% of 30	46 100% of 46
Ratings for each time period:			
A	6 13%	1 3%	0
B	35 78%	24 80%	7 5%
C	4 9%	5 17%	30 85%
Total	45 100%	30 100%	46 100%

were done on 75 (99%) of the 76 children who received home care and died during Phases One and Two. As shown in Table III, information for the period six hours prior to death was available on 68 (90%) of the children, while information for the period one week prior to death was available in only 47 (62%) of the children. The absence of this data is in great part because many of these cases entered home care less than six days before the child died.

Three cards were prepared for each child; each card was identified with a code number, including the child's age and designation by time period as Card I (admission), Card II (one week prior to death), and Card III (six hours prior to death). If the chart did not contain a description of the child at the time period in question, the card was marked "no information available." Thus, 228 cards were prepared--three cards for each of 76 children.

Research staff examined several existing scaling techniques, including an adaptation of the Karnofsky scale (1953), Eastern Cooperative Oncology Group (ECOG) scale (CROP Newsletter, 1978), and Host Performance scale (CROP Newsletter, 1978) to determine their applicability to this study. However, no existing instrument was appropriate for describing the physical condition of children varying from one month to 17 years of age who were dying. As a result, a scale specifically adapted to these children was developed. Drawing from the existing instruments, this scale considers physical characteristics and psychosocial aspects that might occur in these children. Because the intent was to characterize the condition of these children in broad terms, three classifications were developed:

A. Attending school: ambulatory, responsive and interacts well, sleeping well, age appropriate skills and good intake and output.

B. Unable to attend school: ambulatory with help or bedridden, responsive and interacting some of the time, needs assistance with sleeping, control of symptoms and activities, and some interferences with intake and output.

C. Bedridden: not responsive and not interacting, requires special care and assistance with any activity, very limited or no eating or drinking, and diminished or no output.

As intended, progression from A to B or B to C includes increasing severity of symptoms, advancing physical disability, increasing need for assistance, and decreasing communication by the child. Thus, a child with a rating of "C" was more severely affected by his illness than a child with a rating of "A" or "B" and probably required more care. Descriptions of "B" and "C" would describe most hospitalized terminally ill children.

Three nurses independently assigned ratings of "A", "B", "C"

or "Insufficient Information" to each of the 228 cards. All three nurses had extensive experience in pediatric nursing; two had completed post-master's course work in family social studies and the third was a doctoral candidate in hospital and health care administration. The raters were unaware of the histories of the children and did not know whether they died at home or in the hospital. The raters were instructed to view each card from the perspective of a public health nurse visiting a child in the home. They were instructed to assess the child's condition for a research study, rating the child as either "A", "B", or "C".

An example of the narrative included in the cards as follows: Sample Card II. Age six months.

> The child is sitting on her mother's lap. She is whimpering at times. The mother states the child is taking a limited amount of fruit juices. She is constipated. She was very restless during the night and voided once. She dozes at short intervals but appears to respond to her mother's voice.

All three raters independently agreed on a "B" rating for this card.

Table IV

Ratings of Physical Conditions of 12 Children who Died in Hospital During Phase One of Home Care

	Admission		One Week Prior to Death		Six Hours Prior to Death	
Total number of children	12		12		12	
Total with complete information	12		7		7	
Total with agreement of at least two raters	12 100% of 12		7 100% of 7		8 100% of 8	
Ratings for each time period:						
A	2	7%	0	-	0	-
B	10	83%	6	86%	2	25%
C	0	-		14%	6	75%
Total	2	100%	7	100%	8	100%

Tables III and IV separate the ratings of physical conditions for the 46 Phase One children who died at home and the 12 who died in the hospital. Comparison of Tables III and IV shows almost no difference in the ratings of physical conditions between children who died at home and those who died in hospital. This finding suggests that the 12 children who died in the hospital did not exhibit any increased physical disability or severity of symptoms as compared with the 46 children who died at home. It is probable that the children who died in the hospital were not more severely affected by their disease than were the children who died at home.

Differences in Home Care Services

Various aspects of the home care received by children who died at home and in hospital were examined to assess whether they were related to the place of the child's death. The length of time in home care shows no major differences between the two groups. Fifty-eight percent of the children who died in the hospital and 48% of those who died at home received home care for a number of days which falls below the median for the combined group of 58 cases. However, there is some evidence to suggest that children who died at home received a more intensive level of care than those who died in the hospital. Table V shows that the 46 children who died at home received more home visits from home care nurses than did the 12 children who died in hospital. The relationship between dying at home and rate of home visits is significant at the .02 level (Mann-Whitney U). Table VI shows a similar difference in the rate of telephone calls to the family by home care nurses which, however, is not statistically significant.

A similar difference exists in the medications received by home care children. Table VII shows the number of medications used at home during home care by children who died at home and by those who died in hospital. There is a significant relationship at the .05 level between place of death and use of medications.

Table V

Rate of Nurse Home Visits Per Day of Home Care During Phase One

	Rate for 46 Children Who Died at Home	Rate for 12 Children Who Died in Hospital
Median	.42	.21
Range	0.06 - 3.0	.03 - 67
Mann-Whitney U = 381.5; Z = 2.02; p = .022 (one-tailed)		

Table VI

Rate of Telephone Calls Per Day of Home Care During Phase One

	Rate for 46 Children Who Died at Home	Rate for 12 Children Who Died in Hospital
Median	.61	.50
Range	0 - 3.67	.07 - 3.0
Mann-Whitney U = 317.5; $\bar{z}$ = .80; p = .21 (one tailed)		

Table VII

Number of Medications Used at Home During Home Care of 58 Children Who Died During Phase One

Number of Medications	Children Who Died at Home		Children Who Died in the Hospital	
	Number	Percent	Number	Percent
0	0	-	1	8.3
1	4	8.7	1	8.3
2	6	13.0	3	25.0
3	6	13.0	0	-
4	5	10.9	2	16.7
5	7	15.2	3	25.0
6	3	6.5	2	16.7
7	4	8.7	0	-
8	3	6.5	0	-
9	1	2.2	0	-
10	3	6.5	0	-
11	2	4.3	0	-
12	2	4.3	0	-
Total	46	99.8	12	100.0

Mann-Whitney U = 359.5; $\bar{z}$ = 1.60; p <.05 (one-tailed)

Table VIII

Types of Medications Used at Home for Pain Control During Home Care In Phase One

	Children Who Died at Home		Children Who Died in the Hospital	
	Number	Percent	Number	Percent
Narcotic Analgesic	37	80	5	42
Antianxiety Medications	35	76	6	50
Nonnarcotic Analgesics	16	35	5	42
None of the above	0	-	1	8

Table VIII shows that home care children who died at home were more likely to receive narcotic analgesics and antianxiety medications for pain control than were home care children who died in hospital. The frequency of use of nonnarcotic analgesics was about the same in the two groups and the only children who did not receive pain medication at home died in the hospital. Table IX shows this relationship also holds true for medications other than those used for pain control. In most of the medication categories shown in Table IX, children who died at home were at least as likely as children who died in the hospital to receive medications. "Antibiotics" is the only category in Table IX in which children who died in the hospital were much more likely to receive the medication.

Tables X and XI show that the difference in "intensity" of service between children who died at home and those who died in the hospital also holds in the areas of supplies and equipment. Children who died at home used or had available more supplies and equipment than children who died in the hospital.

These data (Table IX - XI) on the "intensity" of home care services clearly show a difference between Phase One home care children who died at home and those who died in the hospital. However, that difference is not in the direction one might hypothesize in trying to determine why some children were readmitted. While one might anticipate that the children who required more intensive home care would be more likely to return to the hospital, these data suggest exactly the opposite--children who received more intensive home care were more likely to die at home. This finding suggests an alternative explanation that parents of children who

Table IX

Types of Medications Used for Symptom Control, Other than Pain, at Home During Home Care in Phase One

Medication	Children Who Died at Home		Children Who Died in the Hospital	
	Number	Percent (of 46)	Number	Percent (of 12)
Corticosteroids	16	34.8	2	16.7
Laxative/enema/ stool softener	15	32.6	2	16.7
Antiemetic	10	21.7	3	25.0
Antibiotic	3	6.3	4	25.0
Sleep-inducing	8	17.4	0	-
Cough medicines	5	10.9	0	-
Antiallergy	4	8.7	0	-
Antihistamine	3	6.5	0	-
Antacid	2	4.3	1	8.3
Antifungal	2	4.3	1	8.3
Vitamin	2	4.3	1	8.3
Antiseizure	2	4.3	0	-
Eye lubricant	2	4.3	0	-
Antidiarrheal	2	4.3	0	-
Diuretic	1	2.2	0	-

died at home were more committed to and more involved in home care, and thus developed and provided a more intensive type of care, than parents of children who died in hospital. In summary, there appears to be a strong indication in Phase One that families who mounted more intensive home care efforts were more likely to have their children die at home.

Information from interviews with parents after the child's death suggests that decisions to return the child to the hospital were hardly ever related to the process of home care. Table XII shows a summary of the reasons parents gave us as to why they decided to readmit their child to the hospital. It is clear that

Table X

Various Room Furnishing and Equipment Used During Home Care in Phase One

	Children Who Died at Home		Children Who Died in the Hospital	
	Number	Percent (of 46)	Number	Percent (of 12)
Room Furnishing:				
Urinal/bedpan/ commode	26	57	0	-
Wheelchair	14	30	5	42
Overbed/bedside table	8	17	2	17
Hospital bed	7	15	1	8
Emesis basin	6	13	1	8
Hospital gown	4	9	1	8
IV standard	3	7	0	-
Bathtub safety equipment	2	4	0	-
Walker	1	2	0	-
Stretcher	1	2	0	-
Equipment:				
Antipressure devices	27	59	5	42
Suction machine and apparatus	7	15	1	8
Oxygen and apparatus	5	11	0	-
Humidifier	5	11	0	-
Blood pressure equipment	5	11	0	-
IV fluids and apparatus	4	9	0	-
Feeding tubes and food	3	7	0	-
Hot water bottle	2	4	0	-
Neck support	0	-	1	8
Whirlpool/sitz bath	0	-	2	17

Table XI

Medical Supplies Used During Home Care in Phase One

	Children Who Died at Home		Children Who Died in the Hospital	
	Number	Percent (of 46)	Number	Percent (of 12)
Incontinence pads	30	65	5	42
Dressings	21	46	3	25
Syringes/needles/swabs	12	26	2	17
Mouth care swabs	9	20	0	-
Urinary drainage equipment and supplies	7	15	1	8
Gloves	5	11	2	17
Antiseptics	5	11	2	17
Enema supplies	4	9	0	-
Masks	1	2	0	-
Tongue blades	0	-	1	8

multiple factors entered into each family's decision. However, these reasons can be grouped into several major categories. One major category includes such personal reasons: "I couldn't go past the room if he died in there"; "I didn't think it was any good for his sitter"; and, "I was afraid her sisters would never want to sleep in their room again." (families 1 - 4). Another category includes reasons suggesting that the mother, as primary caregiver, felt anxious, overburdened and exhausted and had become sufficiently comfortable in the hospital to utilize the hospital facilities to aid her in caring for the child (families 5 - 7). Medical problems such as sudden and acute pain, respiratory distress, and status epilepticus constituted a third category (families 8 - 10). The family that wished their child to receive Laetrile treatment in a hospital did not readily accept nursing visits and had apparently planned a Mexican hospital admission prior to the nurse's first home visit. In addition, families 4 and 8 did not feel they had adequate nursing services.

The delivery of home care services was the major reason cited by a parent in three cases. In one instance, the parent felt that

Table XII

Reasons for Return to the Hospital for 12 Children Who Received Home Care During Phase One and Who Died in Hospital

Family	Reason(s) for Return of Child to Hospital
1	Father and siblings did not want child to die at home; died in ambulance en route to hospital.
2	Child requested return home. Mother told physician and nurse that she didn't want child to die at home. Parents felt that some medical treatment might still help.
3	Child and parents sought readmission to control sudden, severe pain. Mom also related inadequate rest, fear of the death event, and fear the siblings wouldn't be able to use their room again if child died in it.
4	Mother said she planned on rehospitalization when child dying. Felt overburdened at home and more secure in hospital. Mother felt the nurse did not offer enough assistance with physical care.
5	Mother felt anxious, exhausted, overburdened, that home care was too much responsibility for her.
6	Mom anxious, exhausted, concerned that she couldn't help quickly enough. Father felt that the child's presence in home was not good for siblings, nor himself.
7	Mother felt anxious, overburdened and alone in caring for child at home, felt more secure in hospital. Could sleep at night knowing that nurses were responsible. Physician seen as encouraging hospitalization.
8	Child developed respiratory distress. Child requested return to hospital. Family unable to reach nurse and felt lack of support from nurse.
9	Child developed pain, requested return to hospital to establish pain control and to stay overnight. Died before discharge. Mother later reported fear of what death would look like.
10	Mother planned death at home, child readmitted for transfusion when rectal bleeding began. Mother felt poor physician support prevented death at home.
11	Father not accepting of death and cessation of chemotherapy. Family went to Mexico for Laetrile.

Family	Reason(s) for Return of Child to Hospital
12	Rehospitalized for control of status epilepticus. Mother said she wouldn't be able to stand seizures at home.

the physician failed to communicate adequately the seriousness of the child's situation and was not sufficiently supportive of home care. Insufficient nursing services were cited by the other two families. In one case, the family apparently chose to return to the hospital when the nurse failed to respond to their telephone call. In the second family, the mother had always planned on returning to the hospital before the child died.

Differences in Physician Services

The 12 children who died in the hospital were cared for by eight physicians, six of whom cared for one child, one who cared for two children, and one who cared for four children. The latter physician was involved with a total of six of the 58 cases in Phases One through Four, (67%) of his patients died in the hospital and two (33%) died at home. The physician who cared for two of the children who died in the hospital also provided care to four children who died at home. Physician attitude was cited as a cause for return in only one of these cases (family number 10 in Table XII). In none of the other 11 cases was this an apparent factor.

Table XIII shows that in Phase One, there was little difference in the number of physician home visits between children who died at home and those who died in hospital--in both groups, less than one-fourth of the children were visited at home by their physician.

Table XIV shows a difference in both phases in the number of clinic visits between children who died at home and those who died in the hospital. In each phase, children who died at home were twice as likely as children who died in the hospital to visit their physician's office or clinic. A possible conclusion that might be drawn from Tables XIII and XIV is that children who are hospitalized are seen in the hospital by their physicians and are, thereby, much less likely to either need or receive home visits or clinic visits. Alternatively, one might conjecture that difficulties encountered either in transporting the child from home to the clinic or in encouraging the physician to make a house call may have contributed to parents' decision to readmit their child to the hospital before death. However, the absence of supporting data from other parts of this study would lead to the conclusion that return to the hospital was not related to availability of physician services.

Table XIII

Physician Home Visits Prior to Death During Home Care in Phase One

No. Visits	Children Who Died at Home		Children Who Died in the Hospital	
	Number	Percent	Number	Percent
0	35	78.1	10	83.3
1	4	8.7	1	8.3
2	3	6.5	1	8.3
3	3	6.5	0	-
17	1	2.2	0	-
Total	46	100.0	12	99.9

We have attempted to discover whether or not the parents were satisfied with the home care services provided. One of the ways we looked at this was to have the parents rate their choice of care if they had to choose over again. Of the mothers and fathers, 97% said they would definitely choose home care, one might choose home care, and one mother said she would definitely choose hospital care. Of the 46 families whose child died at home, there is one mother who said that although she cared for her child at home, she would definitely choose the hospital if she had to do it again. Of the mothers and fathers whose child died in the hospital after having home care services: six said they would definitely choose home care; one might, four were not sure, one might choose the hospital, and four parents representing two families, would choose the hospital again. The same pattern was seen in the ratings by parents of satisfaction with home care services: 97% were very satisfied with the nursing services provided and 3% were somewhat satisfied. Of the mothers and fathers of the children who died in the hospital, 11 (79%) were satisfied and three (21%) were not satisfied. The three parents who were not satisfied represent two families who would definitely choose hospital care if they had to choose again. It is of interest to note that the two nurses who worked with these two families state that they would not be willing to provide home care services in the future. Examining these instances more closely, there were several areas with these families in which severe communication problems existed between the parents, nurses, coordinators, and physicians.

Table XIV

Visits to Clinic by Children During Home Care in Phase One

No. Visits	Children Who Died at Home		Children Who Died in the Hospital	
	Number	Percent	Number	Percent
0	30	65.2	4	33.3
1	8	17.4	4	33.3
2	1	2.2	1	8.3
3	0	-	1	8.3
4	1	2.2	1	8.3
5	4	8.7	0	-
9	0	-	0	-
10	0	-	0	-
14	1	2.2	0	-
15	0	-	1	8.3
19	1	2.2	0	-
Total	46	100.1	12	99.8

Conclusions

The institutions who assumed the care delivery aspects during the third and fourth year of the grant are the University of Minnesota Hospital Home Health Services Department, Minneapolis Children's Health Center, and St. Louis Park Medical Center, along with the public health nursing agencies throughout the state. The institutionalization of this model of health care delivery for the dying child has now been expanded to include children dying from causes other than cancer at both the University of Minnesota and Minneapolis Children's Health Center.

Findings of this study suggest current practices might be changed with the nurse assuming more responsible and accountable roles than is now the usual practice, with close collaboration with physicians. This study challenges the requirement for a medical director for hospice programs, as well as the requirement for a multi-disciplinary team including volunteers. Direct reimbursement for nursing services would be essential for the cost-effectiveness

to be passed on to the public. Further research needs to be done to determine the benefits and limitations of nurse-directed health care systems.

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FEASIBILITY AND DESIRABILITY: DISCUSSION OF DRS. MARTINSON, NESBIT AND KERSEY'S PAPER

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For almost a decade, a home care project for the dying child with cancer in Minneapolis, Minnesota has been underway with careful concurrent and prospective evaluation. The project in both its phases will long stand as the paradigm of good, justified and compassionate research, combining the best tradition of nursing with the best traditions of inquiry. Precisely because of its excellence in execution and consequent plethora of data, the project does generate reflection and reaction. There were two basic hypotheses tested among several goals (Martinson, 1976, 1977). First, is it feasible to use the home setting for care of children with late stage cancer? Once that was answered in the affirmative, the question turned to the hypothesis that such home care was indeed desirable and, if that were answered affirmatively, the final engineering question was joined whether such home care could be institutionalized through existing health care organizations? There is an interesting full circle quality to that sequence of investigations.

Dr. Martinson considers feasibility and desirability as a continuum which is hard to separate. To quote Dr. Martinson from her paper: "Some threshold level of feasibility must be achieved before an assessment of desirability can take place. For some distance along the continuuum immediately after this threshold level, it is very difficult to distinguish between desirability and feasibility." I would like to take gentle exception to that. Feasibility only means capable of being carried out. The project was always possible, but not necessarily feasible within the realities imposed by prevailing economic, social and philosophical concepts and limitations. Desirability means having pleasing qualities or properties, or worth seeking or doing as advantageous,

beneficial or wise. The project must have been declared a priori desirable under the first definition, otherwise, it would have been a callous cold blooded exercise. By the second definition, desirable becomes a value laden concept that is totally independent of feasible, unless we all weigh our wisdom against pragmatism.

We need to focus in a moment on the wisdom of the project. Wisdom is the combined presence of knowledge, insight and judgement. The project gives us knowledge to a degree hardly ever accumulated in such undertakings. It was done with compassion and, thereby, gave unprecedented insight into the perceptions, feelings, anxieties and hopes of patients, parents and health care providers. Judgement, however, must remain a generator of decision not only on external, but also personal-internal factors. Judgement must continuously introduce the perturbation of the perception of the individual decision maker, no matter how solid the facts and clearly expressed the feelings are.

One must come to terms with the understanding of dying. The concept that dying at home can be a good, a virtue, is unacceptable to those who feel that their obligation to the patient is to fight off death at all costs because death to them is always ugly and undesirable.

On the other hand, death can also be a blessed relief, a hoped for solution to an otherwise insoluble loss of self control. There are those among the health care providers who feel that their responsibility includes the urging onto the patients this solution to their agony.

Dying is a process that can only be acknowledged by the patients themselves. No one can declare another person as dying--that inalienable right of personhood is a right that children possess also (van Eys, 1981). Home care for the dying is a concept that refreshingly reminds us that old fashioned virtues can be reintroduced in spite of our modern medical technology. Institutionalizing home care for the dying is an unfortunately necessary codification of behavior imposed by our complex social and economic structure.

However, we should never lose sight of the perception that the child with cancer is still a child who is a person worthy of hearing. John Holt once said it succinctly: "Wisdom, even as regards these very difficult questions of life and death, is not a matter of age (Holt, 1978, p. 9)." Home care, as an alternative locale for optimal care, is desirable and wise if the child lets us know he or she is dying. When the judgement of the caregiver is substituted for that of the patient or the parent, home care for the dying child is a concept that is feasible but discontinuously nondesirable. I am therefore very grateful for the title of

this paper by Martinson and her colleagues which represents a gradual maturation from previous publications. The copy I received was called "Home Care for the Child with Cancer." Her first papers focused on the dying as the target (Martinson, 1976). It was called, "Why Don't we Let Them Die at Home?" There is even some anger in that title. The dying was included as the motivation of the study (Martinson, 1976, 1978). Later, the living with dying was acknowledged--Home Care for the Dying Child, Living to the End (Martinson, 1981). Now only the home care is mentioned as focus. Titles do set the frame of mind of the reader. This maturation is therefore welcome indeed.

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COPING WITH SURVIVORSHIP IN CHILDHOOD CANCER: FAMILY PROBLEMS

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INTRODUCTION

The death of a family member exerts a powerful psychological impact on those who survive. But what of the family member who "might die" and then does not? The concept of "anticipatory grief" is well known to those who work with cancer patients and their families (Futterman and Hoffman, 1973), but the impact of a threatened loss which does not come to pass presents a rather different set of problems (Kemler, 1981).

It is within this context that I would like to discuss some of the findings of a follow-up project investigating the psychosocial sequelae of surviving childhood cancer (Koocher and O'Malley, 1981). Recent developments in the treatment of cancer have produced significant changes in the natural histories of the childhood malignancies. Children who almost certainly would have died a dozen or more years ago now stand a 50% chance of surviving at least five years post diagnosis. What were once acutely fatal illnesses are now often chronically life-threatening ones. Survival times are longer, hopes of a cure are not unrealistic, and extensive periods of disease-free remission are often the rule, but substantial uncertainty still lingers as a reality for many many years.

My colleagues and I have coined the term 'Damocles Syndrome' to describe the nature of these stresses on pediatric cancer patients and their families. According to an anecdote by Cicero, Damocles was a courtier under the rule of Dianysius I, tyrant of Syracuse. As one is wont to do when in the employ of despots, Damocles lavished great praise on his king in a rather transparent attempt to insure his own survival. In return, Dionysius offered

to show Damocles the true nature of his happiness, and invited him to be the guest of honor at a magnificant banquet. At the banquet Damocles found himself surrounded by every luxury wealth could provide, but his delight faded when he discovered that he was seated beneath a naked sword suspended above his head by a single horsehair. The families of children under treatment for cancer now find themselves in a similar predicament. They may realistically dare to hope for successful treatment or 'cure', while recognizing that disease may recur even after prolonged periods of good health. In some cases the actual treatments for the cancer itself create future risks of their own including organ failure, disfiguring handicaps, or even second tumors in previously irradiated sites.

In this presentation I shall be focusing on the families and siblings of patients who were successfully treated for childhood cancer. The follow-up project I mentioned earlier involved the study of more than 120 individuals who contracted some form of cancer prior to age 18. My colleagues and I interviewed them an average of 12 years post diagnosis when all were disease-free and done with active treatment. We also interviewed 173 parents and 101 siblings of these long-term survivors. The results of the entire project, which took nearly five years to complete, were published last year as: The Damocles Syndrome: Psychosocial Consequences of Surviving Childhood Cancer (Koocher and O'Malley, 1981). This presentation is intended to give you a flavor of some of the central issues for family members during the long and uncertain treatment phases of cancer.

PATIENTS' PSYCHOSOCIAL ADJUSTMENT RATINGS

Each patient was individually interviewed by a child psychologist and a psychiatrist. Both made independent clinical judgments about the person's psychosocial adjustment, and these were combined to obtain an overall adjust rating (Koocher and O'Malley, 1981, Chapter 3). Statistical analyses were conducted on two distinct groups: those with no adjustment problems (52%) and those with mild to severe problems (48%). The mixing of individuals with both mild and substantial residual psychosocial problems was intentionally done so that resulting differences between groups would be all the more powerful indicators of key variables.

Parents were interviewed separately by a social worker, and siblings, who had been at home during the patient's illness, were interviewed by a research assistant whenever they were willing to make themselves available. We did not attempt to rate the psychosocial adjustment of family members other than the patients, but instead used the information gathered from these family members to refine our picture of the patient's adaptation.

The patients' parents turned out to be in good agreement with us as far as their children's adaptation was concerned. The frequency of the residual concerns they reported about their children's welfare was significantly positively correlated with the adjustment ratings assigned by the psychologist and psychiatrist ($p = .001$).

FAMILY CHARACTERISTICS ASSOCIATED WITH FAVORABLE ADJUSTMENT

A number of family variables seemed related to favorable psychosocial adjustment in the survivor group. Some of these factors were economic, but others were clearly linked to the tone of communications within the family. We discovered, for example, that family income and socio-economic status were positively correlated with psychosocial adaptation ($p = .002$). The financial costs of cancer treatment above and beyond direct medical fees (e.g., transportation, parking, babysitting for siblings, special appliances, time lost from parents' jobs, etc.) are staggering, and are not likely to improve rapidly in the current economic climate. Unfortunately, we know that these financial pressures will continue to tax the psychosocial adaptation skills of survivors and their families.

The style of family communications about the patient's diagnosis also seems to yield important implications for long-term adjustment. Clinicians and researchers caring for child cancer patients and their families have often discussed the question of open communication with patients. There are those who hold that seriously ill children and their young siblings should be protected from the knowledge that they are confronted with a life-threatening illness; others advocate open discussion of the diagnosis and prognosis with all family members.

Although the protective approach to communication with child cancer patients was widely advocated in the fifties and sixties, a more open approach has been adopted in recent years by most of those who care for these children (Gogan et al., 1977). Results of extensive surveys conducted in 1961 (Oken) and 1979 (Novack et al.) demonstrate a dramatic shift in physicians' attitudes toward disclosing the cancer diagnosis to both adult and child patients.

Our study provided an opportunity to approach the "to tell or not to tell" issue in a new way. Implicit in the arguments of those who advocate open communication with the family is the assumption that an honest discussion of the diagnosis and prognosis will ultimately result in better psychosocial adjustment for family members and the patient. We therefore decided to examine the effect of the patient's knowledge of the diagnosis on his or her later psychological adaptation, as reflected in our ratings of their current adjustment.

The "protective" approach to communicating with patients was the prevailing philosophy of the treatment center during the years when most of the survivors in this investigation were in active treatment (Evans, 1968). Nonetheless, many parents did choose to tell their children the diagnosis; others accepted the advice of the professional caregivers not to do so. As a result, the survivors in this sample had learned of their diagnosis in a variety of circumstances. We hypothesized that survivors who had learned their diagnosis early in their cancer experience would tend to be better adjusted than those who had been intentionally misled and learned they had cancer long after the diagnosis was made.

Many of the survivors' reports of when and how they had learned of the diagnosis varied widely from the reports given by their parents. Both the retrospective nature of the study and selective memories may have contributed to this fact. We assumed, however, that the critical factor would be the child's perception of the event and circumstances, since this perception would form the chief basis of their responses to questions about how and when they learned their diagnosis and their age at diagnosis. The following criteria were used to assign participants to one of the three groups:

Informed Early. Patient was told the diagnosis by parent or physician within one year; or patient was diagnosed in infancy and was told the diagnosis before age six.

Informed Late. Patient was not told the diagnosis by parent or physician within one year; or patient was diagnosed in infancy and was not told the diagnosis before age six.

Self-Informed. Patient was not told the diagnosis by parent or physician before learning it another way (told by peers, read their own hospital charts, figured it out by reading about their disease or from radio or television information).

Tables were constructed comparing the "well-adjusted" patients and those with "adjustment problems" to see how many from each group had been "informed early" or "informed late." Those informed early were significantly more likely to fall in the favorably adjusted group (Fisher's Exact $p = .008$). A comparison of the self-informed group and the group told by parents or physicians (early or late) for adjustment was not statistically significant ($p = .46$). However, combining all survivors who were not told the diagnosis early (informed late and self-informed) for comparison on adjustment with those informed early did show high statistical significance ($p = .009$).

Open-ended questions dealing with the issue of telling the child the cancer diagnosis were asked in interviews with survivors, their parents, and their siblings. All three groups were asked the

question: "Should a child with cancer be told the diagnosis?" The majority of participants stated that the child should be told, including 90.3 percent of parents (N = 173), 70.1 percent of survivors (N = 114), and 71.1 percent of siblings (N = 101). Very few parents (4.85 percent) said the child should not be told; 22.5 percent of survivors and 13.1 percent of their siblings agreed with this view. In addition to believing that children with cancer should be told the diagnosis, most parents said that in ideal circumstances, children should be told as soon as possible (84 percent), a smaller proportion stating that children should be told when they ask (9.9 percent). Parents often added that whatever the circumstances, the child should be told by age ten. A majority of the 101 siblings interviewed (65.5 percent) thought that brothers and sisters should be told about the diagnosis as well as the patients; 14.5 percent said "Maybe they should be told"; 10.9 percent said that siblings should not be told; and 9.1 percent said they didn't know.

The results of these analyses support the hypothesis that early knowledge of the cancer diagnosis is related to good psychosocial adjustment among long-term survivors of childhood cancer. In addition, the majority of the family members interviewed--survivors, parents, and siblings--believe the child with cancer should be told the diagnosis early, despite the fact that such open communication had been discouraged at the time of the diagnosis years earlier. Many of the parents who did not initially share the diagnosis with their child identify this lack of candor as a source of stress or difficulty both during and after treatment.

Several authors have pointed out that "telling" the child per se is not really the most important issue, and that what should be emphasized is providing a climate of openness and support for the child in dealing with his or her serious concerns (Vernick and Karon, 1965; Waechter, 1971; Spinetta and Maloney, 1975). A primary assumption of our study is that how soon the child was told can be seen as a general indication of family openness both to discussing the disease and its implications and to helping the child cope with fears and anxieties. Of course, it is not possible to show conclusively that such open communication of the diagnosis leads to better long-term psychosocial adjustment in this population, since no data are available about either the children's mental health or family communication patterns before the onset of cancer. But it appears that by using an open approach with patients, professional caregivers can provide models of adaptive behavior for parents. Such modeling could help families with children in active treatment learn healthy, open styles of communicating and coping together.

ADJUSTMENT ISSUES FOR PARENTS

The most critical adjustment problems for parents seem to have been event-linked. That is to say, certain events such as the period of their child's initial diagnosis, changes in treatment, disease recurrences, hospitalizations, and the elective cessation of treatment were all special circumstances requiring extra coping efforts.

Confirming the initial diagnosis for cancer was the most stressful event of all. Regardless of the number of years that had passed by the time of our interview, parents related these events with much evident emotion. The persistence of a given symptom rather than the type of symptom per se was what alerted parents to the likelihood that something was quite wrong with their child and led them to take the child to the physician. The emotional tension for the parents increased, reaching its zenith when the diagnosis of the child's disease as cancer was confirmed at a pediatric medical center. The parents' anxiety level remained high for a minimum of three months to a year or more. The tension at its peak was often described spontaneously by parents as a state of "emotional shock."

The emotional shock gradually dissipated, but stress peaks of lesser intensity were precipitated by new or disturbing events during the course of treatment (e.g., new medication, side effects of treatment, and surgery). For parents whose child had a relapse or recurrence, a new high of tension and stress was experienced, but the "shock" did not last as long as when the initial diagnosis had been made. Another small peak occurred, unexpectedly for many parents, at the end of active treatment, which was most often three years after the diagnosis. At five years after diagnosis, some parents felt that the "magic cure time" had been reached and often celebrated the event.

Nonetheless, most families at the time of interview still noted that their fear of recurrence was not far below the level of awareness, no matter how many years had passed uneventfully. They sometimes described themselves as "lump conscious" or otherwise attuned to any symptoms reminiscent of those which first appeared in their child's case. Individual families represented the spectrum of this fear; members of one family stated flatly that they believed the cancer was over and done with and could not recur, whereas members of another family continued to be globally fearful about recurrence at the time of our study.

PARENTS' COPING STRAGEGIES

The parents were all asked what they thought made it possible

for them to endure the experience. They reported that hope and honest communication were most important. Many mentioned faith, although they were not necessarily referring to their formal religious affiliation. Individual parents said that the support of other family members was very important, especially their spouse. Those parents without spouses felt the absence of their partner acutely and talked of friends or other relatives as being significant. Many parents mentioned that their other children helped them to keep things in some perspective, and others noted that the courage of the patient was what kept them going. Parents also reported that a sense of humor helped them endure some stressful events. Trust that their child was getting the best and most up-to-date medical care possible was essential.

SIBLING ISSUES

Considering the retrospective nature of our inquiry and the fact that the 101 siblings interviewed were of different ages at the time another child in the family was being treated for cancer, it is not surprising that their memories of the events at that time are highly variable. Still, more than half of the siblings interviewed were able to recall at least one or two incidents about life in the home at the time of the patients' illness. Three common threads seemed to emerge from the many different stories told:

First, having a brother or sister with cancer had a sustained and profound impact on their lives. A number of older siblings recall taking on adult responsibilities when their parents left them in charge of the other healthy children in the family; many others who were younger at diagnosis remember the disruption of family routine caused by the illness as only a temporary upset.

Sometimes the disruption of the sibling's life caused by the patient's illness was much more profound than simply taking on extra responsibilities or adjusting to a new household routine. For example, one brother in this sample interrupted his college education and then found himself isolated from his friends when he returned home to help his family during the sibling's treatment for leukemia.

A number of problems seemed to be fairly common experiences during the treatment and were recounted by many of the siblings. They often recalled with disappointment that they were not allowed to visit the patient in the hospital because of age restrictions. Some siblings had problems with other children in school. Occasionally they found themselves having to defend their brother or sister from ridicule for baldness or physical impairment or some other side effect of treatment. In a few other cases, misinformed

neighborhood parents insisted that their children stay away from the cancer patient's siblings, feeling they might be "contaminated." A few siblings felt that they had been called upon to act as a major source of emotional support for one of their parents throughout the experience.

Second, emotional concerns such as feeling left out, jealousy, resentment, and fears for their own health were relatively common among the siblings. It seems that those aged six to 10 at the time of the patient's illness may have been most emotionally vulnerable to feelings of rivalry and attendant difficulties. They were often aware enough to know that problems were at hand, but too often ignorant of details which might have helped them to understand events better. Closed communication patterns contributed to these problems in some families. It seemed that many of the siblings' concerns could have been prevented or ameliorated by providing direct factual information at the time of the patient's diagnosis and treatment. It is clear that siblings should not be neglected by members of the treatment team during the course of a patient's illness. As one local oncologist is inclined to observe, "People don't get cancer, families do."

Finally, most siblings seem to have resolved their feelings of anger and jealousy toward the patient over time following the cessation of treatment. Normal sibling relationships appear to have resumed in most cases. Some siblings even reported positive aspects of the cancer experience including feelings of enhanced closeness to the former patient or other family members. Others reported feelings of personal growth and enhancement of their own coping skills.

IN SUMMARY

The uncertainties and stresses which accompany the diagnosis and treatment of childhood cancer extend far beyond the patient, impacting all members of the family. In the best of circumstances treatment will succeed and the patient will resume a healthy life. As you have read here, however, the emotional residual may be substantial. If they are this striking for those whose family member is "cured," they are all the worse for those who lose a family member. The ultimate message is clearly that we must attend to the psychosocial health of the family unit during all phases of the diagnosis and treatment of cancer.

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NOT EASILY FORGOTTEN? DISCUSSION OF DR. KOOCHER'S PAPER

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The efforts of Drs. Koocher and O'Malley (1981) are unique and valuable, and are worthy of a place among the important works on psychological aspects of cancer. It is unfortunate that Dr. Koocher's paper is too short to cover many of the items the team dealt with in the book. For an audience like this, it would be valuable to read the book itself.

I had thought at first that classical learning and forgetting theory could be applied to how well long-term survivors adjusted. Over time an event tends to be remembered less and less, in a well-defined curve of declining recollection that eventually approaches zero recall. Perhaps one could apply that theory to the gradual dimming of the events of the disease, with associated loss of fears over time. For certain families that theory may hold. But for many others, there is a complication. As Dr. Koocher says, most families are tuned to the slightest hint that perhaps a relapse may be taking place. Whether they communicate overtly or covertly with the child, the family is persistently conscious of, and may be repeatedly reminded of, the disease and its possible consequences, so forgetting among them tends not to take place. Various families may communicate this covert tension to the child. A second reason for abandoning the classical declining retention curve is that the illness experiences took place in an environment of strong emotion. Under those conditions all bets are off with regard to the retention curve. Often such an emotional experience is not forgotten easily, and the curve of retention, instead of dropping rapidly, drops slowly, or remains flat. For others, it may drop even more rapidly than expected and soon become overtly "forgotten" but may govern behavior unconsciously in an important way.

I also tried to fit to the events associated with childhood cancer the idea that the families display a distribution of adaptive capability. This idea fits more easily. Those who adapt to strange situations will come to live more easily with the threat following first remission. At the other end of the scale, those who don't adapt never come to live with it. Perhaps, if one joined coping ability with adaptation, or even considered that they may be closely allied concepts, we might derive some kind of useful theoretical model. That is left as an exercise for those who are deeply interested in models.

The relationship between adjustment and the time when the child is told that he has cancer, early or late, was significant. The thought occurred that the superior adaptive capability of young children to new environments might have something to do with such a relationship, since there was also significant relationship between age and adjustment: the younger the child at age of diagnosis, the better the adjustment. Even though the correlation was admittedly low (.18), it was significant at the .03 level. Dr. Koocher may want to examine this possibility by doing a two-variable analysis, perhaps a Mantel-Haenszel multivariate chi square, to see how much age at diagnosis accounts for the relationship between time when told and level of adjustment.

I then began to think through the whole picture of adjustment. It is interesting to note that the general distribution of adjustment scores in the patients was skewed. Some 78% were well adjusted or had mild problems but with good functioning, and the groups in the remaining 22% taper off in number with more and more severe maladjustment. This is reminiscent of the distribution of maladjustment in the general population itself. Drs. Koocher and O'Malley mentioned the notion that general adjustment level may form the basis for disease adjustment. I suggest that not only could this easily be true here, but that it has been observed in many other life stress and disease situations. Such a phenomenon should be carefully taken into account when looking at factors suspected of being associated with maladjustment, or even causing it.

Lastly, a gentle reprimand for Dr. Koocher is in order. He cited two or three high significance levels: e.g., parents' statements about residual problems correlated with psychiatric judgments at the .001 significance level; family income correlated with adjustment rating at the .002 significance level. He failed to mention that with the substantial number of cases, such significances reflect realtively low correlation coefficients: $r = -.31$ and $r = .28$. In his paper he also failed to mention that the statistic of real interest is how much variance is accounted for by these r's. It is the square of r, 9.6%, and 7.8%, respectively. Neither of these figures is very large, and we should shy away

from regarding the various family data as impressive predictors of adjustment during the survival years. To the authors' credit, however, they did mention all three of the relevant statistics for each relationship in the book.

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THE ELUSIVE NEUROPSYCHIATRIC SYMPTOMS

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In the second Salmon lecture, presented at the New York Academy of Medicine, Michael Rutter (1982) reviews the overwhelming evidence that "it is possible for overt and indisputable brain damage to occur, and yet for a careful clinical examination to reveal no definite (neurological) abnormalities" (p. 22). As a matter of fact, only about one-third (Shaffer, Chadwick, and Rutter, 1975) of such neurologically damaged youngsters show neurological symptoms.

Two elegant studies by Rutter and his associates (Rutter, Chadwick, Shaffer, et al., 1980; Chadwick, Rutter, Brown, et al., 1981; Brown, Chadwick, Shaffer, et al., 1981) clarify a further fact: children with indisputable evidence of Central Nervous System (CNS) injury, with normal neurological evaluations, evidence significant psychiatric abnormalities. Can cognitive and psychiatric sequelae be separated? The CNS injured group without neurological signs or symptoms, and with normal cognitive functions, had several times more psychiatric symptoms than a control group. The brain injury examined was the presence of post-traumatic amnesia of at least seven days duration following accidental head trauma. Highly relevant is that these findings were not present in youngsters who had less than seven days of post-traumatic amnesia, indicating a smaller degree of CNS damage.

The second study used epileptic seizures as the indication of CNS damage. Again, the rate of psychiatric disorder in this group was several times that of the normal control group, even in epileptic children with normal cognitive (i.e., I.Q.) capacity, and absence of neurological signs and symptoms. In both areas of injury, trauma and epilepsy, the greater the degree of CNS damage, the presence of cognitive defects, the presence of neurological symptoms and signs,

the larger the incidence of psychiatric symptoms.

Of what interest is this data in a symposium on childhood cancer? A major contributor to the increased survival rate of children with acute leukemia deaths from about 70% to less than 10% (Pochedly, 1977, 1979), and the greatly prolonged remission time of systemic leukemia followed the introduction of intrathecal methotraxate and cranio-spinal radiation with 2,400 rads (Aur, Simons, Hustu and Veroza, 1972). There are about 15 medical center studies, including the Memorial Sloan-Kettering Cancer Center-Downstate Medical Center participation, that are systematically looking at the effect of various alterations in prophylactic CNS treatment of leukemia (Pochedly, 1979).

Why this interest? Bresnan (1972) documented that a significant number of children treated for nonresectable brain tumors with the combination of intrathecal methotraxate and radiation develop widespread leucoencephalopathy. Pizzo and associates at The National Cancer Institute (Pizzo, Poplack and Bleyer, 1979) found that 29% of patients who had received the combined prophylactic CNS treatment had "abnormal CT scans similar to those observed in patients with overt leucoencephalopathy" (p. 135). They further state that obvious (neurological) clinical abnormalities were not associated with these findings. In marked contrast, Meadows (1982) describes an average I.Q. drop of 15-20 points in youngsters treated with the combined prophylactic CNS treatment. The drop in I.Q. was not seen in the first retest (12-34 months after treatment), but in the second (3 plus years after treatment). Further, the drop was not seen in all patients, but was restricted to the 2-5 year olds, and to the older, brighter youngsters (I.Q. 110-132 at initial testing). This study was prompted by a desire to document what had been a general clinical impression that Dr. Meadows was uneasy with; "the kids seem to do well in school". A systematic assessment of psychiatric symptomatology was not done by that group; the general impression is that the youngsters do not have major emotional difficulties (Meadows, personal communication, 1982).

One obvious purpose of this presentation is to bring together the findings from the pediatric, the cognitive, and the psychiatric literature: psychiatric symptoms must not be seen as alternative to neurological or neuropathologic symptoms, as either/or, but rather it behooves us to see that neuropathological findings can result in neurological abnormalities, in cognitive defects, and in a host of psychiatric symptoms. Psychiatric symptoms can have a second etiologic origin, namely as a response to the psychosocial stresses on child and family produced by the fact of having a life-threatening illness whose treatment can be prolonged, painful, and disfiguring. As Koocher (1981) points out, the life of the survivor is not risk free, rather can best be described as the

Damocles Syndrome (Koocher, 1981).

A second reason for this presentation is to highlight that neurologic, cognitive, and psychiatric symptoms, even if they eventually have far reaching consequences, can be missed even with careful evaluations. This is, in part, because of the natural reluctance by staff to heap further difficulties on the child and family with cancer, and in part on the reluctance of the medical staff to deal with an additional set of problems in an overwhelming medical situation for which little might definitely be done. A second, and perhaps more profound reason why these symptoms may be missed is that neurologic, cognitive, and psychiatric symptoms in the child and early adolescent can very easily be missed and not recognized because they are much less clear and distinct than in the adult patient. Treatment strategies can be more precise when etiologies are more clearly recognized (Christ, 1978).

I will now present a case of just such a situation, one, however, where a psychiatric diagnosis and extensive treatment were done with a youngster whose symptoms are more probably unusual manifestations of temporal lobe epilepsy secondary cerebral anoxia. I present this case to highlight the current state of the art of diagnosis, a state to whose remediation a study of the ALL survivors may contribute.

CASE PRESENTATION

Milton is now 19. First referred to me at 12, he came as a psychiatric patient. The parents described behavioral outbursts at home and in school, not learning, and many episodic "scared feelings" described by the boy as feeling "like there is a big man standing behind me who will take me away", all starting at age eight following an anoxic episode, probably caused by a cardiorespiratory arrest, 2^{o} to intravenous Valium treatment for suspected status epilepticus. The parents wanted my help in finding an appropriate school where Milton could progress academically.

Milton is the fourth child of a Jewish middle class family. The father runs a family haberdashery store; the mother is a school teacher. The eldest child died of cancer at age three (Christ, 1982). The next two were academically superior recipients of State Regents Scholarships. Milton had mild measles at age 12 months, shortly after he developed progressively more severe asthma. By age six, he was already on steroid medication, and was rushed to a local hospital as often as twice a week for treatment of acute asthmatic attacks. He was referred to an outpatient psychiatric clinic at age six to see if psychotherapy might alleviate the asthma. He was seen in weekly play therapy for one year. He was

described as bright, outgoing, friendly, with a good sense of humor. His play showed a preoccupation with anger and destruction. The parents were seen as infantalizing the boy in selected areas: he took a baby bottle during asthmatic attacks and at times to sleep. The psychotherapy did not alter the asthma.

The boy was sent to a research asthma center in the midwest at age eight. He came home after six months for the Christmas holidays. His older brother described that Milton fell unconscious on his way to the bathroom while they were playing Monopoly. The brother was frightened by the appearance of spittle on Milton's lips, and the blue color of his lips and fingernails. There were no seizure-like movements. Within one hour, Milton was at the local hospital. They treated him with intravenous Valium for possible status epilepticus, during which Milton had a brief cardiorespiratory arrest. He was transferred to a university medical center in Manhattan. Milton was comatose for 24 hours. He did not recognize his parents for 48 hours. Extensive neurological evaluations showed a rapidly improving memory deficit, and 2-4 per second EEG waves, indicative at this age of CNS pathology. He improved rapidly, and was returned to the asthma center for continuation of treatment.

Repeat neurological evaluation at a medical center showed nearly normal EEG and no neurological signs of CNS pathology. Behaviorally, he was described as changed by the staff of this midwestern asthma center. Formerly outgoing and a leader with his peers, he now had frequent scared feelings, rage outbursts including, at times, running away from the center, was now ostracized by his peers, and was reclusive and played by himself. He was diagnosed as having a severe emotional problem, probably related to the separation from home, the anoxic episode and subsequent traumatic neurological evaluations. He was then started in intensive psychotherapy at the asthma center.

Milton was discharged, having completed the prescribed year's course of hospitalization, with a diagnosis of steroid dependent intrinsic asthma and an acute anxiety reaction. The parents found the boy unchanged as to the severity of the asthma, but now additionally found themselves with a youngster with severe fears, episodic severe behavior outbursts and with a health class teacher and principal who frequently complained about his behavioral outbursts.

One year later, Milton was returned to the asthma center for an additional year of hospitalization. A repeat neurological evaluation still showed no pathology. The EEG was now interpreted as normal. The emphasis of the hospitalization was again on the control of the behavior through psychological intervention. The asthma remained unchanged.

The family came to me two years later. Milton was now 12 years old with the symptoms described above, requesting help in finding a more appropriate school placement. In my initial assessment, I was impressed by the obvious emotional strengths of Milton, by the absence of emotional problems in our interaction that would be consonant with the severe emotional outbursts or with the frequent scared feelings if these were exclusively of psychogenic origin. He happily beat me at checkers, yet showed severe memory defects. He did not know the names of his teachers or fellow students. Direct questioning clarified he could not even remember whether he had gone to school that day.

The possibility of hippocampal damage 2^{o} to the anoxic episode resulting in a memory defect and temporal lobe epilepsy accounting for the temper outbursts and the scared feelings seemed a likely possibility. A sleep EEG taken just before the videotape was made that will now be described, showed bilateral temporal spikes. A second tape, taken when he was 19 1/2 years old will then be described.

The differences and similarities in these two tape excerpts are startling. Originally a small Cushingoid playful youngster, he now looks like a muscular young man who appears mildly depressed. The lack of personality development is evident already in his child-like behavior at age 12, more startling in the similarities in his interests, reactions and humor to the first tape at age 19. Milton is seen walking into the interview room, quite obviously very pleased and excited. He has just come from looking at the videotape control room, where he saw his father walking into the taping room and heard him talking through the microphones.

Milton: You mean I can see myself on television?

Dr. C.: Sure.

Milton: Oh! Goody, goody!

Dr. C.: Could you sit on the chair?

Milton: I'd rather sit on the couch.

Dr. C.: The chair is better because the TV camera can pick up our pictures better than on the couch.

Milton: O.K., I like the couch, but I don't mind.

(Milton is a small, pudgy, pleasant youngster. He has previously described he has a "large stomach and big cheek" because he is on steroids for control of his asthma. His whole

way of relating to the examiner, his comments about where to sit, etc. are reminiscent of a lively, early latency age child.)

Dr. C.: So, anyhow, your parents will be watching us in the other room, and then next week we can look at the tape together if you like.

Milton: Oh gosh! My medicine. (He takes out a spinhaler from his pocket.)

Dr. C.: What's your medicine?

Milton: You call it a spinhaler - I put it in my mouth and spray it twice, cause the medicine comes out of that little hole there.

Dr. C.: You carry it with you all the time?

Milton: No, not <u>all</u> the time.

(Milton shudders uncontrollably, with a sudden inspiration, looks a bit frightened.)

Dr. C.: What is the matter?

Milton: (Shudders again) Do be quiet! Would you tell him to get out of here before I punch him in the face? Yes, that's what I'm gonna do, squeeze that guy (smiling, as if this is a shared joke)!

(Milton's humor about his anxiety attacks are evidence of well-functioning defenses; however, the type of humor is more like a bright early latency age child rather than a 12 1/2 year old early adolescent.)

Dr. C.: Tell me what are those like, when you go like that. (Mimics the shudder.)

Milton: I can't help that cause they surprise me, I think.

Dr. C.: What's it like?

Milton: It feels as though someone, a big man, is behind you and trying to take you away and grab you, you know, and hurt you bad.

Dr. C.: Any idea what that somebody is?

Milton: No.

Dr. C.: No idea at all?

Milton: I'm not scared of anybody, unless a big man come near me. (smiles)

(Milton's description of the image that accompanies the "scared feelings" is encapsulated and clearly ego alien, not described as a youngster might describe a delusion or hallucination.)

Dr. C.: Those scared feelings have been going for some time now, I think. When did they start? When did they first start?

Milton: Probably after I had the seizure...I don't know.

Dr. C.: After the seizure?

Milton: I don't know. I think so, I don't think it was before the seizure. I don't think so. I don't remember. Ask my parents. (Milton shudders--mumbles)

Dr. C.: I can't hear you.

Milton: I said, don't get mad, just get angry. It makes you laugh.

Dr. C.: That's what you try to do, make a joke out of it?

Milton: Yeah. I try not to get mad.

Dr. C.: Why?

Milton: Because when I get mad, I do bad things. (Sardonic smile)

Dr. C.: Really?

Milton: Yes.

Dr. C.: What kind of bad things?

(Milton's description, and demeanor while he describes the "bad things" he might do are again reminiscent of a much younger child.)

Milton: I might hurt myself, I might bang my head against the wall, things like that.

Dr. C.: Really! Have you ever done that?

Milton: Yes. See these marks? That mark there (pointing to his left index finger). I couldn't take it anymore. You know I just kind of hurt myself.

Dr. C.: Oh really!

Milton: Sometimes I just can't take it anymore. After it happens all day long. And I start crying sometimes.

Dr. C.: They are really nasty, aren't they! You mentioned that you tried to hurt yourself. Did you feel it would stop them, or was it just that you were so angry?

Milton: No, I just get mad at myself, you know, and I just can't take it anymore.

Dr. C.: And so what you did there was to peel the skin off your finger?

Milton: Yeah, I did a little.

Dr. C.: Can I see that again? There's a little bit of a scar.

(There is a young child-like quality to his description about his scars--they are barely visible quite old, well-healed scars--again reminiscent of a 6-7 year old's interest.)

Milton: It didn't hurt me at all.

Dr. C.: Yes, it looks like an old one...

Milton: It is.

Dr. C.: How long ago was that?

Milton: I don't know. I have one on my foot (pointing to his ankle).

Dr. C.: What was that?

Milton: I had four IVs, and they leaked, it was this place here.

Dr. C.: Oh wow! You mean it got real big like a balloon?

Milton: No, it just swelled and there was a hole in my foot, but it healed up.

Dr. C.: Ah.

Milton: I couldn't even walk on it, it hurt so bad.

Dr. C.: Really?

Milton: They had it stuffed with something, I don't know what they stuffed it with. I have marks on my foot you can see where the IV was. Want to see it?

Dr. C.: Sure.

(Quite startling in a 12 1/2 year old is the total lack of self-consciousness. Without hesitation, he offers to take off his "dumb shoe", and comments about his "long johns" as he rolls them up to show another barely visible totally healed old scar.)

Milton: Find it, I have to take off this dumb shoe. (Comments as he takes off his shoe.) I've got long johns on. You see right there? (Pointing to his ankle at a barely visible well-healed scar.)

Dr. C.: Oh, yes.

Milton: And you see that, that's the scar for that.

Dr. C.: It looks like an old scar though--that happened how long ago?

Milton: I am not sure, I know it was at least two years ago. I am not sure now. Ask my parents, they will know.

Dr. C.: Yeah, they will remember about that. Is it hard for you to remember when things happened?

Milton: Sometimes, I forget how old I am. I'm not sure, but I don't know why I forget that, but I remember when I was born and what year.

Dr. C.: What year were you born?

Milton: 1962

Dr. C.: How old are you?

Milton: Thirteen or 12? Twelve, am I? (looking quizzically at examiner.)

(As he puzzles about his age, his memory defect is becoming more evident. We saw a little of this when he deferred questions of historical facts to his parents. Very subtle, but clearly of great impact is the ease he has in dealing with this defect, so it is easily overlooked. In other situations, when his parents are present, he quite naturally gets them to supply factual information. The frontal lobe "executive" abilities are functioning well. There is a good integration of defenses and interpersonal skills--one senses that this process is automatic.

Dr. C.: You're telling me? (smiling)

Milton: I think I am 12.

Dr. C.: What month were you born?

Milton: May 6, 1962.

Dr. C.: I see.

Milton: I am a birthday present! (smiling broadly)

(Milton's obvious pleasure in the family joke of his being a "birthday present" and elaborating this with statement about being gift wrapped is again reminiscent of a much younger child. He was born on his mother's birthday.

Dr. C.: Is that what it is?

Milton: I always ask her, was I gift wrapped when I was born? That's what I ask her sometimes. Was I wrapped up with a bow? (Giggles)

Dr. C.: You were a real birthday present! So you are about 12 Milton?

Milton: Twelve or 13 I think.

Dr. C.: Do you know what year this is?

Milton: 1975

Dr. C.: And you were born in?

Milton: 1962

Dr. C.: So, when would you be 13?

(The extent of Milton's memory defect becomes clearly evident. The simple arithmetic involved in figuring out his age is easily within his grasp and experience. The problem, rather is the confusion that sets in when he has to remember, in this case, to subtract 1962 from 1975, then figure out the months.)

Milton: In 1973? (pause) No, I would be 11. (Looking puzzled and a little sheepish)

Dr. C.: Yes

Milton: 1974

Dr. C.: When will you be 13?

Milton: 1973? What is this? (Looks more puzzled, laughs a bit.)

Dr. C.: I got you all mixed up here! (smiling)

Milton: I know!

Dr. C.: Yeah, how come? You think it's the TV or something?

Milton: Am I on TV? (looks very puzzled, clearly does not remember he was on TV.)

(More startling is that five minutes into the interview, he has forgotten, not just momentarily, but clearly quite permanently, that he is being videotaped. His original pleasure in being on TV was not a reaction formation against such severe apprehension that repression could explain the dynamics of this interchange. This profound memory defect is substantiated by numerous such episodes, such as forgetting whether he had been in school the day of an interview, forgetting where my office is after he has regularly been coming for a number of years, etc.)

Dr. C.: Sure!

Milton: Where is the TV?

Dr. C.: In the other room.

Milton: Can I see it?

Dr. C.: You can see it as soon as we get through. You can look at it for a little bit. Next week you'll see it again, yeah. You see, what they are doing is they are taping the whole thing. (Milton smiles his sardonic smile, then exaggeratedly sticks his tongue out at the TV camera and makes a face.) There you go! (laughing) You can do it that way! Oh well, you can see yourself doing that.

Milton: Is anybody looking at me?

Dr. C.: Your mother and your dad.

Milton: (Laughs, obviously pleased and excited.) They are going to say: There goes that silly goose!

(Milton's pleasure in being called a silly goose, or a meatball hero, again are reminiscent of a much younger child.)

Dr. C.: Yeah?

Milton: They call me silly goose.

Dr. C.: Hey Milton, one thing I wasn't quite...

Milton: I like that (pleased smile)

Dr. C.: You kind of like

Milton: being called a silly goose, or a meatball hero.

Cr. C.: Is that what they call you?

Milton: Oh we used to have meatball heroes out west.

. . .

Dr. C.: Why do you think you have those?

(The sudden increase in these spasmodic shudders accompanied by "scared feelings" may have been triggered by the discussion of the anoxic episode, "You couldn't

recognize your parent." Most of the time, however, they appear as if out of nowhere with no discernable trigger. The vivid frightening feelings are part of what distinguishes these from severe ties. Further, this escalation, ending in the seizure-like episode, makes one think of a temporal lobe like seizure. The confirmation of this by the EEG was helpful. The question whether the "scared feelings" were miniseizures, aura like phenomena or something else remains somewhat unclear. Important, however, is that the seizure medication nearly eliminated their phenomena.)

Milton: Is it from the seizure or something? That's what it seems like as I never had it before that.

Dr. C.: So whatever it is, it was something that happened at that point?

Milton: When I didn't know anyone, maybe I was just so scared.

Dr. C.: You think so?

Milton: Yes.

Dr. C.: Like it terrified you at that point?

Milton: It happened when I didn't know anybody, I didn't know my parents and I was scared of them, and then they took me in and I got scared.

Dr. C.: Can you remember anything about now?

Milton: No, no.

Dr. C.: It's just really what people have told you about it?

Milton: Yes. I didn't know anybody, that's the only thing I remember them telling me. So I really couldn't remember that could I? (Laughing, the joke being he could not remember now if he couldn't then!)

Dr. C.: That would be hard to remember! (Laughing) When you think about that, Milton, you know, that there was a period when you couldn't even recognize your parents. How does that make you feel?

Milton: Funny you know.

Dr. C.: Kind of scared?

(Milton has five or six shudders--scared feelings in rapid succession. His eyes are downcast, he mumbles, doesn't respond to the examiner's questions--appears momentarily out of contact--all last about 15-20 seconds.)

Dr. C.: Couldn't quite hear you. (pause) What are you feeling?

Milton: Really bad scared feelings are coming, really bad now.

(Milton is clearly looking depressed and dejected, quite in contrast to the previous humorous, lively affect. This affective state lasts about five minutes, gradually wears off.)

. . .

Dr. C.: Have you been practicing the multiplication table since I last saw you?

Milton: I don't remember.

Dr. C.: Cause until you really, really learn them, you have to practice them over and over again. Are you ready? Ready?

Milton: Mm no. (smiling broadly, obviously teasing the examiner.)

Dr. C.: Go! (Milton is shown cards that have the problems written on them like 7x5+=)

Milton: 7 x 5 is 35

Dr. C.: Great!

Milton: 7 x 7 is 21

Dr. C.: Forty...

Milton: Forty-two

Dr. C.: Forty...

Milton: Forty-four

Dr. C.: (Turns the card over, which has the problem and the answer) 7 x 7 = 49. Say the whole thing.

Milton: 7 x 7 is 49. I have said it. I said it wrong to see if you knew it. (smiling broadly)

Dr. C.: Oh is that so? (smiling)

Milton: (Laughing loudly) I didn't really!

Dr. C.: Now say the whole thing.

Milton: 7 x 7 is 49. I've said it! (teasing)

Dr. C.: Do you know why I am doing that Milton?

(In this segment, various methods are explored to see how memorization can perhaps be aided. Since Milton has good frontal lobe executive abilities explanations of why repetition is needed are given.

Milton: Why?

Dr. C.: Cause, ah, remember with the poem that you memorized? It was hard for you to remember the first part of it. But once you started that first line, you remembered the whole poem. Can you remember it now?

Milton: What?

Dr. C.: The poem.

Milton: How does it start?

Dr. C.: Try to think of it. What was it about?

Milton: I am thinking about a song.

Dr. C.: What song is that?

Milton: Aquarius

Dr. C.: Oh, no, that isn't it.

Milton: I remember how it starts (starts to sing the song).

Dr. C.: Yeah, see if you can remember how the poem starts.

(An attempt is made to see if Milton can associate, and use this as a method of finding the poem he has memorized. This memory aid has not been helpful to Milton. Once memorized, memory retrieval (remembering the poem memorized over six weeks ago) is assessed, and appears intact. The repetition of the memorized poem emphasizes Milton's ability to retrieve to him, hopefully, enhancing his sense of mastery and effectiveness.)

Milton: What was the first word? The...(pause)

Dr. C.: Go ahead, keep going.

Milton: Is it right?

Dr. C.: I am not going to tell you!

Milton: I don't know it.

Dr. C.: It's hard, isn't it, you can't remember the animal either?

Milton: Spider?...

Dr. C.: You ready?

Milton: mmmmm yeah, I can't think of it.

Dr. C.: Want me to tell you?

Milton: Just tell me the name.

Dr. C.: There

Milton: was a little spider

Dr. C.: There was a little turtle...

Milton: Turtle, who lived in a box, he climbed on, no, he swam on the puddle, he climbed on the rocks, he snapped at a mosquito, he snapped at a flea, he snapped at a minnow, and he snapped at me. He caught the mosquito, he caught the flea, he caught the minnow, but he didn't catch me. (Obviously very pleased)

Dr. C.: Isn't it amazing? Once you get started, the whole thing is just like a phonograph record. That's why I want you to say the first part of the multiplication table 7 x 7,

and then the rest of it will follow once you really learn it. It's almost like the poem.

Milton: 49

Dr. C.: Hey! fantastic, yes sir!!

Milton: Oh gosh! You frighten me! (Teasing obviously pleased.) 7 x 3 is 23, I don't know.

Dr. C.: No, 7 x 3 is 21

Milton: That's close.

Dr. C.: Very close. You can say that.

Milton: Oh, 7 x 3 is 21, 7 x 3 is 21, 7 x 3 is 21. (Doing it to rhythm, which we had also tried) 7 x 6 is...

(Saying the multiplication table to rhythm, snapping his fingers has also been tried to see if that aids his memorization.)

Dr. C.: Just say it

Milton: is 36

Dr. C.: Almost, it's 42

Milton: That isn't almost! (teasing, laughing)

Dr. C.: That's true! 7 x 6 is ...

Milton: 7 x 6 is 42.

Dr. C.: Say it again

Milton: 7 x 6 is 42, 7 x 6 is 42 mmmmm (incorporates it into a crooning like melodic line)

(Singing the multiplication table to a melody is also a trick. Here, Milton spontaneously starts on 7 x 6 = 42 with a song.)

Dr. C.: Good

Milton: 7 x 10 is 70, that one I know easiest, the 10 tables. 7 x 12 is 84.

Dr. C.: Beautiful, beautiful, you got it!

Milton: 7 x 2 is 14

Dr. C.: Beautiful!

Milton: 7 x 8 is 61

Dr. C.: Almost, 56 say it.

Milton: 7 x 8 is 56

Dr. C.: Think about it.

Milton: 7 x 8 is 56

Dr. C.: Think about it.

Milton: 7 x 8 is 56 (Exaggerated frown, as if concentrating very hard.)

Dr. C.: You know what, Milton, do me a favor. When we go through it now, if I give you the answer, try to imagine the answer written under it, okay?

(The request to visualize the answer to see if visual memory might enhance his memorization, is also tried, but was not helpful.

Milton is now 19 years old. He has been talking about how he had "recently" discovered rules of numbers that he uses as alternatives to memorizing the multiplication table on our way to the videotape session. That he is at the transition between preoperational and concrete operational cognitive development can be surmised from the way he continues the conversation, even though he knows we are starting to tape the interview. His affect is subdued, perhaps depressed. How much of this is due to the anti-epileptic medications and how much to the accumulated difficulties he is encountering is hard to say.

(Milton had been explaining how he multiplies times 20 as we walk into the videotape room. In the seven years since the previous tape segments, Milton has continued to "figure out" number principles. He used all of them before when he was 12 years old, but they now are more practiced. His ability to describe what he is doing is reminiscent of early concrete

operational capacities [reversibility]).

Milton: You know how you would do that?

Dr. C.: No, how would you do that?

Milton: You would double the number that you are "timesing" and then add a 0.

Dr. C.: Give me an example.

Milton: Like 10 x 3, let's say. I mean 20 x 3, you would double it, like you would put it, making it 6 instead of a 3, and then you would add an 0.

Dr. C.: I see. Could you give me another example? Give me a harder one.

Milton: 20 x 30 that would be (hesitates) 600.

Dr. C.: Very good, very good! So that's how you figured that one out! And then you were telling me that otherwise multiplication it is like adding.

Milton: 30, you would triple it, and then add a 0, you know, the same idea.

Dr. C.: Very good, very good!

Milton: Ah, I found that out! (laughing)

Dr. C.: That's very good Milton!

Milton: Cause I notice I would always, a lot of times, I would count 10, 20, 30, 40, and I noticed there was always a 0 on every number, even when I went out in the hundreds, there is always a 0, never any other number at the end.

Dr. C.: I see, so regardless of what happens that always...very good.

Milton: That's how I found out.

Dr. C.: Tell me about the adding, though, you were saying that multiplication is like adding. How is it like adding.

Milton: Like 10, 12, (hesitates) well, like 5 x 5, well you could just count 5, 10.

(There is some perseveration. He continues with 30, adding 0's. Later, when asked to add, he continues with 10, with some hesitation, he finally gives an example of adding.

Dr. C.: I see, I see. So that way you just keep adding them?

Milton: Yes

Dr. C.: Ah, ha.

Milton: You know, you just keep on adding like if you going to... 7 x 3 right here you just do 7, 3, 6, 9, and you keep on adding 3s.

Dr. C.: Go ahead.

Milton: 3, 6, 9, 12 you just keep on adding.

Dr. C.: Keep on adding, until you get all seven numbers. 7 x 3. Show me how you would do that.

Milton: Well just use my fingers sort of.

Dr. C.: Go ahead, show me.

Milton: 3, 6, 9, 12, 15 (hesitates) 18, (hesitates) and 21.

Dr. C.: Very good, very good Milton. Do me a favor. Do another one okay? First erase your fingers. I'm teasing you a little bit!

Milton: Oh you mean the idea! (laughs)

Dr. C.: Yeah, yeah just the idea.

Milton: You mean, erase your mind! (laughs)

Dr. C.: Right, right. But close your eyes and imagine now that you're gonna do it with your fingers, and you are gonna do 8 x 3 without opening your eyes now, okay? Go ahead and use your fingers.

Milton: 8 x 3! (smiles and giggles)

Dr. C.: Yes

Milton: I'm gonna do that one a different way.

Dr. C.: How were you going to do that one?

Milton: I was gonna do 10 x 3 is 30 and then take away 6.

Dr. C.: Oh I see, I see, that's how you do the eights!

Milton: That's how I do some of them also.

Dr. C.: Ah, ah.

Milton: That's another tricky way (smiles broadly, obviously very pleased.)

(Milton takes great pleasure in his multiple "tricky ways" of using numbers concepts to substitute for memory. This process, and his affective reaction, are reminiscent of an 8 - 10 year old youngster.)

Dr. C.: Ah, that's very tricky. So that's how you do your...

Milton: That's how I could do it.

Dr. C.: Let me give you a harder one then.

Milton: But isn't that a funnier way?

Dr. C.: Yeah, that's great, that's great!

Milton: You just take away (laughing).

Dr. C.: Do you do fours that way too? Do you know to do the fours table? Try it this way. Close your eyes now, okay, and do 4 x 6, but go ahead and use your fingers.

Milton: What do you mean just 4 x 6? 4 x 6 (mumbles) 24.

Dr. C.: Great! Now tell me how you did it. What trick did you use that time?

Milton: All I did was 6 x 4, and then I did 6 and 6 is 12 and 12 and 12 is 24 (laughing).

Dr. C.: I see, okay. Now how about 7 x 4. How would you do that one?

Milton: Then I do the same thing, but then I would just add a 6 and that's 30 I just figured it out cause the other one was 24.

Dr. C.: So 6 x 4 is

Milton: 36

Dr. C.: No.

Milton: Not 36 no, no 26, 6 x 4 is (figures it out again) 24.

(Milton's stumbling on 6 x 4 = 36 shows how greatly he is hampered by the lack of memory.)

Dr. C.: Milton, how about in just trying to memorize it? Like, if you had to memorize that 7 x 8 is 56, how would you do it?

Milton: You mean how would I memorize it?

Dr. C.: Yes.

Milton: I don't know.

Dr. C.: Because memorizing is hard for you.

Milton: Not really, if I am concentrating on it, lately.

(Milton's use of the defense of denial is evident. Unfortunately, his feelings that he just needs to concentrate to remember, although it enhances the denial, also lends itself to his blaming himself for the memory defect, and can increase his feelings of self-blame and depression. Repeated efforts to interpret this sequence have to date been unsuccessful.)

Dr. C.: You mean, if you concentrate, you think it helps?

Milton: You mean remembering? Yes.

Dr. C.: Hmm, hmmm.

Milton: Not really, it's thinking. I have found that out. Cause a lot of times I have found out that I just scared to think. Cause I'm can remember phone numbers easy. So whenever I think about it, I can do it.

Dr. C.: And your feeling is if you really concentrate hard, that helps it somewhat? What's the worst thing about the memory problem that you have Milton? What's the hardest

thing for you with that?

Milton: I just forget names sometimes. I don't know what the hardest thing really is.

Dr. C.: Does it get you into difficulty at times? Or do you have trouble with remembering sometimes?

Milton: Like how?

Dr. C.: That's what I was wondering about.

. . .

Dr. C.: The people that come buying this stuff, are they the people that have been there at the horse races?

Milton: I don't know. They might be some of them.

Dr. C.: And ah, you go with your parents?

Milton: Some of the people selling the stuff might be the people from horse racing.

Dr. C.: Oh?

Milton: I don't know.

Dr. C.: And ah, do you go with your parents, or do you go by yourself?

Milton: I go with my parents.

(In the sixth segment, I'm exploring the extent of his interests--he has been going with his parents to sell at a flea market in one of the race tracks. He clearly is not interested in the fact that this is a horse racing group, the type of natural interest one would expect in a late latency or early adolescent youngster. His humor and play on words are reminiscent of the earlier tape and of a younger latency age child.)

Dr. C.: Ah.

Milton: I wouldn't know how to get there at all.

Dr. C.: You wouldn't know how to get there?

Milton: Mm, mm (Shaking his head exaggeratedly)

Dr. C.: Well how do your parents get there?

Milton: They go by car.

Dr. C.: I see, I see.

Milton: Just like how we come here.

(Milton enters into a condescending, teasing interaction with the examiner. The examiner acts dumb--a type of humor often enjoyed by 5 - 7 year olds, but resented by mid-latency or adolescent youngsters.)

Dr. C.: So you drive, ah, yes.

Milton: My father drives (slight sardonic smile).

Dr. C.: Your father drives. I see.

Milton: My father drives, my mother doesn't. (Broader smile.)

Dr. C.: Your mother doesn't drive. I stand corrected. Okay.

Milton: I drive a different way (broad grin).

Dr. C.: How do you drive?

Milton: I drive people crazy!

Dr. C.: Ah, that's your way of driving!

Milton: (laughs loudly)

Dr. C.: Has anybody ever said that to you?

Milton: mmm yes. (smiles)

Dr. C.: Yes, who has said that to you?

Milton: My parents.

Dr. C.: Your parents have said that to you? I see. I see. What do you have to do to drive them crazy?

Milton: I do a lot.

Dr. C.: What's your secret of success?

Milton: What do you mean? (looks clearly perplexed. He has missed the humor).

Dr. C.: How would you succeed in driving your parents crazy?

Milton: (Smiling) By sometimes making jokes or doing something.

Dr. C.: I see. What kind of jokes?

Milton: I don't know. Stupid jokes, like. Not really a joke, I don't know. I am not really sure.

Dr. C.: So, anyhow, it sounds like you kind of know how to drive them crazy, but it's hard to remember how you do it, but it has something to do with jokes?

. . .

Dr. C.: When are you gonna be 20?

Milton: Next year.

Dr. C.: Next year?

Milton: '82.

Dr. C.: I see, okay.

Milton: Don't you know? Couldn't you figure that out? (smiles condescendingly).

Dr. C.: Well, how would I figure it out?

Milton: When I was born, you could just ask me when I was born.

Dr. C.: True, so let me ask you. When were you born?

Milton: Oh, let's see if you can figure it out. I'll be 20 next year.

Dr. C.: Okay, and next year is, nineteen...what will be next year? Can you tell me the year?

Milton: 1982

Dr. C.: 1982 and if you are gonna be 20 then, that means you would've been born 20 years before that...

Milton: So what year was I born?

Dr. C.: You were born in 1963? (Milton is hugely enjoying my errors--broad smile). No, 1961? 1962?

Milton: (Humorous condescending smile and tone of voice) You're good in that, you're good in math!

Dr. C.: Ah yes, always at the top of my class, yes sir!

Milton: You know, if I am born in 1962, right, well, I'll be a 100 years old, you know when that would be?

Dr. C.: You tell me.

Milton: 2062, then on May 6, 2062 May 6.

Dr. C.: Fantastic. You want to live to be that old?

Milton: I wouldn't mind. You are really not too old. You're never too old. You can be too young, but not too old.

CONCLUSION

Milton brings out a number of important factors: some of the etiologic variance in psychiatric symptoms, such as severe fear reactions and explosive temper outbursts can be accounted for by CNS pathology. What turns out to be a profound memory defect can be missed and its manifestations misunderstood when there are good frontal lobe executive functions and good ego defense operating. Two interpretations of the history and findings in Milton can lead to far-reaching theoretical implications. One is the heretofore unsuspected profound relationship of memory defect to personality development; the second is that CNS damage in a young child does not necessarily result in the development of compensatory functions. In fact, it may be that some of the manifestations of CNS damage, such as the drop in I.Q. (see Figure 1) that Meadows (1981) described, may not be manifest for several years.

I have been impressed that the etiologic variance in psychiatric behavioral manifestations in patients can best be accounted for by the predominance of or, more often, combination of six, etiologic variables:

I: Psychodynamic Intrapsychic factors
II: Cognitive factors
III: Neuro-psychological factors
IV: Developmental factors

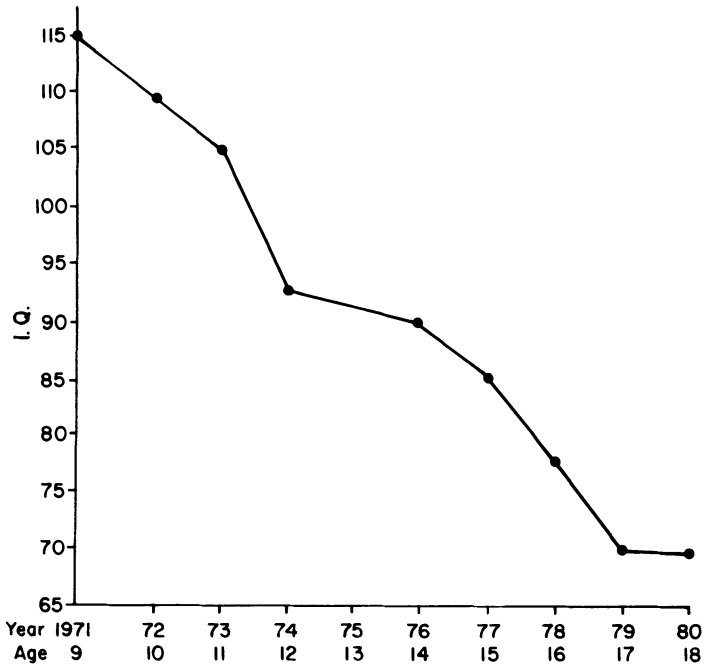

Fig. 1. WISC full-scale I.Q. of M.S. Age 9-18 years.

V: Family interpersonal factors
VI: Socio-cultural-economic factors

The study of the effect of CNS damage on the production of neurological, cognitive, and psychiatric symptoms has been hampered by the absence of comparison data before the injury so that change, or lack of change, can more readily be related to the CNS damage. The careful study of the ALL survivor would seem to provide an opportunity for just such a study. This process has begun. A refined continuation might result in an important contribution to the further refinement of the manifestations of CNS damage in all three behavioral parameters--the neurologic, the cognitive, and the psychiatric.

This presentation highlights the importance of doing long-term follow-up on youngsters like the ALL survivors, suspected of CNS damage. The initial very careful neurologic, psychologic, and psychiatric evaluations within the first two-three years did not

show the extent of the impact of the CNS damage. The follow-up seven and twelve years after the "seizure episode" show the gradual accumulated impact of this damage.

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DAMAGE TO THE DEVELOPING BRAIN AND SUBTLE PSYCHIATRIC CONSEQUENCES: IMPLICATIONS OF THE CASE OF MILTON: DISCUSSION OF DR. CHRIST'S PAPER

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Dr. Christ has focused our attention on a problem of central importance, not only in the treatment of childhood malignancies, but in the broader field of psychiatry and human behavior. American psychiatry and psychology have tended to neglect the role of the neural substrate in behavior and affect. The case of Milton is a beautiful illustration of the role that insult to the central nervous system (CNS) may play, both directly and indirectly, in influencing psychological function, and of how even well-trained clinicians may ignore it as a result of their theoretical preconceptions.

As Dr. Christ noted, studies of behavioral disturbance in various populations consistently reveal an increase in a broad range of psychiatric problems associated with CNS deficit. Such deficit affects higher mental functioning in at least the following ways:

1. Direct impact of the disorder on behavior or affect, as in the disturbances associated with complex partial seizures.

2. Deterioration of cognitive function as a direct consequence of tissue loss or electro-chemical disturbance.

3. Weakened ability to cope with stress or novelty as a consequence of impaired cognitive or affective capacities.

4. Psychological response to the CNS impairment itself and to the patient's awareness of the extent of damage suffered.

Most studies of oncologic psychiatry initially focused on the

last of the above dimensions, the psychodynamic, and neglected those phenomena more directly related to CNS integrity.

It is even more surprising that oncologists have only recently begun to explore these areas, given the well-known neurotoxicity of radiation (Furchtgott, 1975) and the capacity of methotrexate to produce encephalopathy (Kay, Knapton, O'Sullivan, Wells, Harris, Innes, Stuart, Schwartz, & Thompson, 1972).

Milton's case provides a concrete illustration of the value of careful neuropsychological assessment in differential diagnosis and in understanding cognitive deficits and their impact on personality development. As Dr. Christ reported, he felt fairly certain after his initial examination of Milton that the boy suffered from serious CNS damage despite the negative findings of previous neurological examinations. At that point, he asked me to evaluate Milton. My findings supported his impression and the test results specifically implicated the temporal lobes and possibly the limbic system. This helped convince the neurologists to pursue Milton's evaluation further, ultimately resulting in his having one of his "neurotic anxiety" attacks while attached to an electroencephalograph. Simultaneous spikes were observed in the temporal lead recordings, confirming Dr. Christ's initial impressions.

It would be desirable to summarize concisely the neuropsychological effects of current treatments for pediatric malignancies. Unfortunately, the confusion in this area makes such a summary impossible. Most of the studies that have been done have involved acute lymphocytic leukemia (ALL) and the effects of treatment programs involving radiation and/or various chemotherapies, primarily intrathecal methotrexate. The dramatic decline in mortality from ALL is primarily the consequence of effective prophylaxis of CNS leukemia involving the delivery of substantial amounts of radiation to the brain and intravenous or intrathecal administration of methotrexate (Pochedly, 1979).

It appears to be well-established that some ingredients of the treatment protocols can cause severe brain disorders such as leukoencephalopathy, CNS calcification and cerebral necrosis (Ch'ien, Aur, Verzosa, Coburn, Goff, Hustie, Price, Seifert & Simone, 1981; Kay et al., 1972; Price & Jamieson, 1975). Such pathological findings are accompanied by clinical observations of dementia, paralysis and even death (Kay et al., 1972; Pizzo, Poplack & Bleyer, 1979). In some series, there is evidence of more localized damage as in Ch'ien et al.'s (1981) finding of a predominance of fronto-parietal impairment, while others have found more generalized destruction.

More than the above can only be said tentatively, because

of contradictory reports in the literature. Some investigators have found that radiation by itself has neuropsychological sequelae (Meadows, Massari, Fergusson, Gordon, Littman & Moss, 1981), others that methotrexate alone has such sequelae (Kay et al., 1972), and still others, that only a combination of the two is destructive (Price & Jamieson, 1975). Some report that current treatments have no subtle neuropsychological effects (Eiser & Lansdown, 1977; Soni, Marten, Pitner, Duenes & Powazek, 1975), and others that such subtle deficits occur in a majority of the children treated (Meadows et al., 1981; Moss, Nannes & Poplack, 1981). Still others report that CAT scan findings are deviant (Esseltine, Freeman, Chevalier, Smith, O'Gorman, Dube, Whitehead & Nogrady, 1981), while yet others report normal findings (Allen, Deck, Howieson & Brown, 1981). In short, the relevant literature appears to be in a state of generalized confusion.

This is not the appropriate place for a detailed analysis of the reasons for this confusion. In part, such findings are inevitable in an area that has only recently begun to be studied intensively. Some findings are the consequence of the problems associated with retrospective studies, and others may be related to the sizeable patient loss due to death. However, at least some of the disarray is avoidable. Investigations of the neuropsychological consequences of treatment have suffered from poor experimental design, failure to assess a broad range of neuropsychological functions with appropriately specific procedures, and the use of poorly designed tests or of tests that do not measure what they purport to evaluate. Many reported studies have failed to assess attention, the broad range of memory, or new associative or concept learning, even though it is well established that some brain injury can leave psychometric intelligence relatively intact while seriously impairing the ability to learn new material or solve new types of problems. Few studies have assessed psychological states in any systematic way. Often the term "neuropsychological" has been used more because of its current popularity than because of its characterization of the work done.

The case of Milton underlines the importance of precise examination of the data. If we simply looked at the IQ scores that Dr. Christ reported, we might conclude that a general deteriorative process was occurring. However, analysis of the raw subtest scores reveals that Milton attains scores that are the same or only slightly better than those he obtained at the time of the trauma. In effect, Milton has been frozen in time, and what we observe is a failure to add information to long-term memory.

We would get similar results were we to analyze Milton's memory solely by a test such as immediate digit span. This would indicate that his memory functioning was essentially normal, and

indeed, his short-term memory is. However, it is now well-established that the term "memory" encompasses both short-term and long-term phenomena, as well as different levels of processing, at least some of which are localized in different brain areas. It would thus be possible to conclude that no deficit exists where, in fact, serious but specific damage is present.

I would emphasize that we know that brain damage has a variety of general and specific effects on cognition and personality, and that we are fairly certain that current anti-leukemia therapy has generalized neurotoxic effects in many patients. However, we know relatively little about more specific types of impairment. A number of studies are currently in progress with ALL patients that may identify specific cognitive deficits, but they still do not appear to be studying behavioral or emotional outcomes in a sophisticated way. It also seems clear from several studies that neurotoxic effects can be seen behaviorally or cognitively before they are evident on physical measures. The questions to which we do not have any clear answers include:

1. Are there specific cognitive symptoms associated with specific treatment protocols?

2. Are there specific psychiatric symptoms associated with specific treatment protocols?

3. What effects are associated with which ingredients of treatment programs?

4. How do variables such as age, medical condition on diagnosis or length of treatment affect ultimate neuropsychological status?

5. Do some of these deficits manifest themselves only years after the treatment is terminated, and does the deficit become more incapacitating over time?

Given our knowledge of the general neurotoxic impact of our therapies and our ignorance of many specifics, it seems essential to include careful, well-designed cognitive and neuropsychological studies as part of the routine evaluation of pediatric cancer patients in general and of those being treated for ALL in particular. This would seem especially important in light of the preliminary evidence that even adults may suffer cognitive impairment from systemic chemotherapy (Silberfarb, Philibert & Levine, 1980). Such studies would help us decide which of two treatment protocols with equal mortalities is preferable and at what point in time subtle neuropsychological damage becomes evident even before the appearance of physical findings. Clinically, such examinations would enable us to make specific academic plans for the child, to alternate mainten-

ance strategies if the disorder becomes evident, and to separate the consequences of more purely psychogenic problems from those directly related to iatrogenic illness. Sophisticated neuropsychological and neuropsychiatric monitoring should probably become a routine part of pediatric oncology.

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PSYCHOLOGICAL ISSUES AND FUTURE DIRECTIONS: GENERAL DISCUSSION

The following is an edited transcript of the presenter-audience question-answer and round table discussions.

I. IMPACT OF NEWSPAPERS AND TELEVISION

Shirley Shufer - Mental Health Consultant

I want to comment about newspaper articles and television programs, and their importance for the lay public. Interest in these may reflect the public's need to get more information that is not forthcoming from the medical profession. It seems to me that today's conference might reflect just that, since there are no parents on the panel who are quite sophisticated and could address some of these issues. I am wondering if some of the panel would comment on this?

Mrs. Christ

I would underscore the importance of the positive effect of a lot of the information that has come out over the last couple of years. The example I gave of the girl who said she is learning so much from T.V., supports this contention. More of our patients are benefitting from the increased information in the press and on television about cancer which has certainly helped them to feel less stigmatized, less isolated, and less different. If the information is correct and not distorted, it helps our families feel more a part of the human race than they had felt in the past. We have frequently heard patients say that.

Dr. van Eys

I would like to comment on all three points that you made. Parents and patients are a very good source of information about what the experiences are like. At our institution we have started a learning resource center where all the information that we could muster for the parents is available. However, when we surveyed the use and usefulness of the material, we found that many parents

used it extensively, but that the teenagers did not want to have that much information. So you can't always assume a priori that more is better. We were very surprised. We thought that of all the groups, the teenagers would have wanted most of that information. They didn't and they specifically turned their backs on it.

II. STAFF BURNOUT

Kushalata R. Jayakar, M.D. - Director of Pediatric Liaison, Downstate Medical Center/Kings County Hospital

I want to direct this question to Mrs. Christ. From the amount of cases and the follow up that you have presented, it seems like there is a large amount of mental health staff utilized year after year. This must be taking a lot out of staff. They are not immune to burnout. I have done work with cancer patients, but after two years, I just quit. How are staff problems dealt with, prevented, or anticipated?

Mrs. Christ

Margaret Adams has worked at Sloan Kettering for nine years. I think I will let her take this one.

Ms. Margaret A. Adams

I am not quite sure how to begin to answer that. During my nine years of doing this kind of work, I have looked to my team members for support. I needed them to help me, and they in turn got help from me. As a group, all of us get together to share some of the experiences that we have had to face. All of the social workers have a tremendous amount of respect for the physicians and the nurses that we work with, which is reciprocated. That is also very helpful. We are able to be ourselves with each other, and talk over the experiences that we have when they are troublesome. I wouldn't say that I didn't feel sad when kids that I worked with were close to death, but sad is not the same as depressed. It's okay to be sad, but I would have been worried if I had been depressed. So I try to maintain some perspective on it.

I think the other thing that probably helped all of us in mental health is to get as much medical information as we can. We attend meetings like pediatric grand rounds and tumor boards which helps us gain a more accurate perspective on the real nature of the illness and its treatment. It's important not to focus only on your own part of the work. By gaining some knowledge of the overall treatment development and the progress that is being made, we can get a broader picture than just what we ourselves are doing.

Mrs. Christ

One thing I have heard the social workers talk about frequently is their tremendous respect for patients and families. I sense the staff feels it a privilege to be involved with people and see how amazingly well they are able to cope at this particular point in their lives with extraordinarily difficult situations. There is a tremendous admiration and respect which develops, that gives the social worker a perspective and a sense of being privileged to participate with the patients and families in their integrative coping processes. That is another important factor that counters burnout.

Dr. Christ

I was wondering, Mr. Parker, if you might be able to address the question from the perspective of nursing staff gradually acquiring competence in doing what they are doing? Have you found this to be an important element in countering burnout? I suspect that if there is a continued feeling of professional growth, a continued feeling of personal development, a continued feeling that one is learning, that this may result in one's own sense of growth which counters burnout?

Roger Parker, R.N.

I have always viewed burnout as deficit spending. I would highlight Mrs. Christ's remark that if one avoids deficit spending, it can be considered a true privilege to work with people who will accept the help that we offer. In putting the whole cancer question into perspective, I tell people that there is no inherent promise that life is painless and problem free. Those of us who are in the helping professions have a real opportunity, and as Grace Christ said, something of a privilege to be in a position where we can reach out and touch others in a meaningful way. In order to avoid deficit spending, one has to keep that whole thing in perspective and avoid the kind of situation where you overextend yourself, you are over involved, or you are dealing in an arena in which you do not have the energy or perhaps the interest and the skill. If you avoid those situations, and frequently bouncing off peers and colleagues is the way one does that, and take care of your own mental health, your own needs, then you can avoid burnout. I challenge each of the nurses who work with me to avoid deficit spending. How do you do that? I think the answers are different for each individual. But somehow we have a tendency to play "ain't it awful" with the cancer question. I have not found that to be true. Some of the most meaningful experiences in my life as a nurse have been helping people who were dying, as well as those who were living. I have my own answer for avoiding deficit spending. Each person has to deal with that themselves.

Dr. van Eys

I would like to make a very brief comment about this. First of all, at M. D. Anderson, we help each other by having an annual conference where we discuss this issue. One of the things that comes through very clearly about the people who burn out, which incidentally, I don't call deficit spending but bankruptcy declaring, are the ones who were in the profession because they needed a child. Since a child could not always give what they needed, they get into trouble. The ones that do very well are the ones who really don't need the child, just as the parent who has the accepted but incidental child probably does the best. The ones who wanted the child very badly, or did not want a child at all, do very poorly. And so we tend to weed out the ones that are in there for their own sake.

Dorothy Wimmer - Hospice Nurse, Jersey Shore Medical Center, New Jersey

I have a practical question about the kinds of support which you offer in your various institutions to the general staff who are doing the hands-on-care of these patients, day in and day out, and interacting with these families on a regular basis.

Ms. Adams

I can describe support groups at Memorial Sloan-Kettering. We have weekly psychosocial rounds on our inpatient units for staff who are involved with the children which includes the social workers, nursing staff, psychiatrists, house staff, attendings, head nurse, chaplains and recreation people. The major focus of the rounds is on patient management and care planning. Often we need a chance to talk about our own experiences with the patient before we can make plans for how to deal with that person. Especially if it's a troublesome situation in which we are feeling very sad or angry, we need first to spend time with ourselves. There are also more formalized support groups. The pediatric social workers meet as a small unit. The pediatric nursing staff has two ongoing monthly meetings which I also attend. These meetings are really important to me because we are able to talk about our experiences on the unit and provide each other support and perspectives on the kind of care that we are giving.

Mrs. Christ

Sometimes this staff support is harder to achieve in a community hospital where everyone isn't working with cancer patients. At Memorial Sloan-Kettering we create an atmosphere which allows people to react to very strong emotionally stimulating events. It's

accepted that staff will respond to it and nobody thinks that they are having a psychotic depression because they are crying in the middle of the day. It is quite striking among social workers who come to our educational programs from community hospitals around the country. They find this atmosphere most surprising. This atmosphere isn't the norm in other institutions which allow staff to express and work on their emotional responses to these very strong stimuli.

Dr. Flomenhaft

Can we hear about how other institutions provide staff support?

Dr. Martinson

First, as a professional you have to come to the realization that most of the time you really are not hurting as much as the family. You have to face this, because you do have the option to leave and that alone should help you realize that the family has no choice, while you and I do. After eight years of the home treatment project, I would say most nurses can work in these situations even though they think they cannot. But you may also run across a few individuals who really think they can, but cannot, based on their own individual abilities, background, and experiences. Interestingly, during the stressful moments of their work, most of the nurses had found considerable support from their own family, including spouses, parents and siblings. No doubt, the support derived from one's colleagues at the work place was important. However, in my travels around the country, I have become very concerned that there are some hospice staff who are spending more time supporting themselves than they are the families. I am not saying that the work place should not help here, but it should not be spending more energy on supporting staff than on family. Finally, until fairly recently, it was hard for us as a society to think realistically about death--that actually death would come. Now, I am a little bit more hopeful as a society, because we are aging, and as we have more and more people who are in their eighties, we are going to become more aware of death around us.

Carlene Lucashensky - Nurse Practitioner, University of Connecticut Health Center

Speaking as a nurse practitioner, I am having a lot of difficulty lately with trying to leave the hospital behind. I work both in outpatient and inpatient services. Presently, our social worker is on maternity leave and provision for much of the emotional support is up to me and the other nurse whom I work with. After a day's work, some nights we are on the phone with parents from 6:00

P.M. to 11:00 P.M. It's hard to stop talking with a mother who calls up about her 17 year old son with T cell leukemia who has a very bad prognosis, and, in the midst of all this, her husband died two months ago of colon cancer. She says that she needs somebody to talk to, and you are the one. Instead of talking for a half hour, she goes on and on and then she hangs up. Then Mrs. so and so calls. I feel that if I am ever going to be burnt out, it's going to be this week.

Dr. Flomenhaft

So what do you do on the weekends?

Carlene Lucashensky

They call me on the weekends too. They don't care, no time is sacred to them.

Dr. Martinson

Your experience is very similar to when I began in nursing. No doubt we have to be responsible to our patients. What I suggest you do is to try to get a local nurse to assist you. We have to realize that none of us can do it all alone, and maybe, you've got too heavy a caseload right now. Why not find out if there is a nursing network available in your community, one nurse helping another nurse? One of the things we found terribly helpful is that when the nurse in the hospital got to know the public health nurse who lived close to the family, she could ease the burden. When that nurse needed help, she could in turn call you. You might want to make a public health nurse referral for supporting the family on an outpatient basis. Perhaps, too, if you had a good mental health clinic network available in your state, that might be an appropriate kind of referral for someone who is having a lot of trouble coping.

Dr. Flomenhaft

Could that be a distinction between a large and small community where there isn't sufficient personnel and resources available?

Dr. Martinson

It seems to me that there must be some more people around who can help out, but that can happen in a smaller community.

Mrs. Christ

There are a couple of other possibilities in this situation. Maybe there is just too much work to do, when someone else needs

to do it. As we become more sophisticated, we are able to focus more clearly on the issues, intervene more quickly, and take less time. The reality is that it will take a toll on you. If you aren't able to set limits, either by being clearer in your focus, more goal oriented in what you do, or cut down on the actual number of patients, you will burn out.

Dr. Christ

I'm referring to the previous question, where you were asking how to deal with the mother who keeps calling very frequently. I think one area that can mistakenly be left out, is that at times one is dealing with psychopathological responses. As psychiatrists, we often deal with an aspect of a patient's need that might not require that it be met. More difficult to deal with is the person whose excessive calling may not only be because of excess stresses, but also because an underlying problem, such as being a passive dependent individual, who may be trying to have you be something that you are not. She might want you to be a protective mother, somebody who will take over responsibility, somebody who will make her feel better rather than just someone who might help with a particular problem. I think it is essential to try to make such a distinction.

It is also important to decide whether or not you can handle the emotional problem. It is helpful to be clear about how to refer such a person to someone else. That type of referral can be very difficult, because if somebody is very upset, perhaps crying with you, and emotionally involving you, you might feel like a real bitch if at that point you say, "I don't think I can really help you. I think you need somebody like a social worker, a psychiatrist or somebody like that."

One way of keeping a perspective is, if you think about the last fifty patients that you have had contact with, my guess is that you will have one or two at most who will involve you as much as the patient you described. That would be about right in terms of the incidence of psychopathology. If you have as many as ten out of fifty, then you might want to ask, "Hey, what am I doing that might invite such over involvement?"

Dr. Flomenhaft

Maybe you are over-estimating your importance and under-estimating certain significant others in the life of that family. I hear your sense of responsibility and commitment, but you are going to burnout. I think you may want to consider who else is in that network beside the professionals.

Mrs. Christ

Setting limits is not an easy thing to do with a family like this. It is important to do, and one has to learn how to do it but it is not easy!

III. STAFF DISAGREEMENT

Pulluru Rao, M.D. - Pediatric Oncologist, Downstate Medical Center - Kings County Hospital

I have a question for Dr. van Eys. Your staffing conference is different from the tumor board conference where the more medical decisions are made. Now if you have the same kind of format in both conferences where there is a disagreement as to what kind of treatment should be the primary treatment, how do the parents and the child feel when the doctors argue and disagree about the best form of treatment for the child?

Dr. van Eys

I think it will be a very odd presentation to present certainty to the parent and the child when none exist. We have had no difficulty arguing about it from the various points of view.

Mr. Parker

Frequently, we get into an issue of blame around things that don't go well, particularly around some of these very difficult situations. We have to recognize that the questions are very complex and the answers are not simple and the decisions are painful to make. The patients are frequently ambivalent; the families are ambivalent; the nurses are ambivalent; and the physicians are ambivalent. We give each other a lot of mixed messages. Just as it is sometimes difficult for the physician to resolve the question, it is equally difficult for the nurse to resolve the question. Many times the kind of data the nurse gives the physician is absolutely opposed to where she/he feels that particular patient is or ought to be.

We need to focus on staff relationship and communications in order to develop a mutual supportive atmosphere and not one of blame or fault finding. Just as one may wonder where some interns are going to medical school these days, I wonder where some nurses are going to school. Yes, there are physicians who don't understand pain control, but there are nurses, likewise, who don't understand pain control. If you get into a blaming situation, it can be very destructive to everyone. But a mutually supportive environment in which you work at making the answers and the pro-

posals clearer can lessen the ambivalence in many of these situations. Not expecting everybody to be perfect in these situations can go a long way to help people avoid burnout.

IV. TREATMENT OF TERMINALLY ILL CHILD

Meir Salameh, M.D.- Pediatrician, Coney Island Hospital

My question is with regard to the treatment of the terminal child where the decision is taken to stop all medication and the parents are told that they can take the child home and expect him to die. Are we increasing the suffering of the family? It could be two weeks, maybe a month before the child dies. Are we increasing the suffering of the family by disconnecting all the treatment and telling the family to go home? Could we, for example use a placebo? I want to refer to one point made by Dr. Miller in his presentation. Our purpose always should be stressed that we are treating the patient, never to say to the parent, "We have no more medication." If this is our purpose, how can I say in the terminal case that I have no other medication, take him home and let us wait for him to die?

Dr. Miller

Let me take the last one. I agree with you, we never say, "There is nothing more I can do." There may not be another phase one chemotherapeutic agent that we can offer, or it may not be appropriate because the patient may not survive to really get any benefit from the new drug. But it is easy to pull a drug off the shelf and say, "That's what I will do", if it makes you feel like you are doing something. I think the most difficult task a physician and staff have in treating and supporting a terminally ill patient is in providing the kind of support that doesn't entail mixing up a drug and shooting it in someone's vein. It means talking with the family and listening to them. Many of the families don't want to go home. They need the support and the input from the medical staff and the nursing staff. They are very frightened about their child dying at home.

Dr. Ida Martinson spoke about the alternatives, that is, the preparation for children to die at home when families feel comfortable about that. It is very easy to give medicine to a patient but very difficult to provide supportive care in a family where everyone understands that yes, this child is dying. There is an awful lot of supportive care that can be given like relief of pain and making a child more comfortable in terms of even simple blood transfusions. Sometimes, it may not make very good medical sense to continue platelet transfusion in a child who is totally refractory to platelet transfusions. It makes no sense to go

through the cosmetic effort of making it look like you are doing something, when what you are doing is of no help. Families can understand if it's simply and clearly explained to them, that yes, we give platelets, but the platelets are of no benefits to this child whatsoever. All we are doing is making things look good on the surface.

I don't think we ever reach the point where the physician says there is nothing more that I can do. I think that's what leads patients to unorthodox and unconventional therapies because you've given up. There is much more that you can do, but, unfortunately, no one teaches you how to do that in medical school and in residency programs. It is something that one very painfully learns how to do, because there are no guidelines for it. It is the most difficult, most painful, and most exhausting thing that one can learn. It is why you leave the hospital with not very much left to play squash at night. You have given it all. But no, I don't think we ever imply that there is nothing more that we can do.

Mrs. Christ

I did not mean to imply that we would ever say to someone that this is the end of our relationship and we are no longer caring for them. The message has to be given very, very strongly that we are still involved in caring for them medically, socially, and emotionally. If anything, that's a stronger message at this point than at other points in the treatment process. Where there may be no more drugs, a family may need to hear that rather explicitly if they have been involved in treatment for a number of years with one drug after another. Certainly, we would not leave them alone. We continue care even more aggressively in a social, emotional, and physical sense than, perhaps, we had before.

Dr. Miller

I want to pick up on a point that Dr. Martinson made with reference to the judgment of over-treatment. We have to be very careful about whose judgement that is. We have to listen to the families of patients whom we are treating, if we are very much involved in a developmental chemotherapy program. The more I listen to families, the more I hear them say, "We are not ready to give up yet." The judgement about over-treatment is one that we shouldn't be making, particularly, how and when we see patients who do get an extra four or five months or even a year of effective life when we might have given up the battle.

The other reality is that we now have other ways of salvaging some of these patients. We can transplant bone marrow in patients who may have had two or three relapses; if they do have a complete remission, they can be cured. We even now have experimental tech-

niques which will purge the bone marrow of leukemic cells, even in the absence of HLA match sibling, so that we can use parents as donors. There are chemotherapeutic tools and immunological tools to clean out bone marrows in order to use autologous marrow transplants. The only way we are going to get those children in shape for that is to "over-treat" them. I see all kinds of red flags on whose decision it is about over-treatment.

Dr. Martinson

I am glad you brought that up because I hold the physician accountable for this decision. I think a family member does not know whether it is over-treatment or not. I hold the physician absolutely accountable here. What I meant by over-treatment is the physician who has put the patient through every latest procedure, but still continues treatment. That's why I am willing for physicians to earn as much, but also they must be willing to make the decision and then be honest about it.

Dr. Miller

Putting the patient who has failed all of the developmental chemotherapeutic agents on a respirator...

Dr. Martinson

That's what I really oppose, and I just hold the physician accountable.

Dr. Koocher

One of the critical factors in whether or not a patient will sign a consent form for treatment is personal experience rather than what information is printed on the form itself. Dr. Miller's point was that the personal experience of those of us who work with these patients is very different from the personal experience of people in general. What I did in an unpublished study was to show a consent form for bone marrow transplant to physician oncologists, oncology nurses, physical therapy students and a group of adults in an adult education psychology class. I posed the following problem to the subjects: Your child has aplastic anemia, one of the less severe forms, and has an identical twin who is healthy. Would you sign the consent form for a bone marrow transplant? After they answered, I then asked them, if you were the patient, would you sign the consent form? The vast majority of them were willing to sign for a child, but not for themselves, indicating that they can make the decision not to have treatment for themselves, but wanted their children to have the chance offered by the treatment. The one exception was the oncologists who wanted more data on the tissue type. The point is that we have to watch the

dilemma that Dr. Miller has noted about how we the professionals make our decision. These decisions are based on all the patients we have seen, some of whom have not done well at all, which may be biasing us into being ready to give up before the family is ready.

Dr. van Eys

We have to be very careful in these arguments to avoid lumping together all medical institutions. Dr. Miller and I both work in a well known comprehensive cancer center and we treat a highly selected group of patients who surely don't come to our center to give up. Patients who come to M. D. Anderson or to Memorial Sloan-Kettering have made the decision to continue until the last dance is still realistic.

Dr. Flomenhaft

For those of you in the audience who come from community hospitals, I wonder if there are any comments about Dr. van Eys' remarks?

Dr. Martinson

In Minnesota, almost all the childhood cancer gets treated down at the University Center in Minneapolis. The community physicians refer all their childhood patients to the center.

Maureen Moore - New York

I do have experience with community hospitals in Connecticut, where I have found a reluctance to treat to the end. There is a reluctance to put children on parenteral nutrition because of a pessimistic outlook on how long the children can live.

Noel Griffis

I am a nurse at Montefiore Hospital which is a large medical complex in New York City. I work on a 40 bed adolescent ward. That is a lot of sick adolescents to have together at one time. We have a number of them who come onto the ward with cancer. These are kids ranging in age from 12 to 22 years, with different types of sarcomas and all kinds of everything and anything. The dilemma is that we have some kids who want to die and their parents say, "No, you can't, the doctors are supposed to do everything." We have some patients who don't want to die, but the parents have given up. We have some kids who want to die, but the other patients won't let them die, and the doctors say, "You can't, we are going to do everything we can." Previously, only patients 18 years and older were able to sign consent forms, but then we lowered the age

to 16 years. Now, there is discussion of bringing it down to 13 years of age when the patient can sign consent forms. I just want everybody to think about patients who are 16 years of age, and even younger to be considered responsible and mentally capable of making these life or death decisions. We have 13 year old terminal cancer patients who say, "Forget it, cut the lines." There is a 17 year old female who cries out, "Let me die." But her parents are saying, "No, no, no." The two doctors who are in charge of her care are in sharp disagreement about what should be done. Finally, she was sent home and the parents were taught how to take care of her. The patient doesn't want anything else. The hematologists are fighting with the family to get her back into the hospital.

Dr. Rao

At Kings County Hospital Center, we have a 13 year old patient with ALL who has relapsed multiple times, but he wanted to live. I was going to ask the question about the children's desire to live and length of survival. I felt that the 13 year old patient really was not going to make it beyond a week or 10 days, yet he made it for three months with all the hematological problems because he had a tremendous desire to live. I just wanted to ask Dr. Koocher to comment on that.

Dr. Koocher

One of my interests happens to be forensic issues and the capacity of people to give consent. The only anecdote I can tell you which is relevant to Dr. Rao's comment is about eight year old Larry who had been in the hospital four times in six months, with a suppressed immune system and fulminating infections which were treated with intravenous antibiotics. Prior to his fourth admission, which was right before Christmas, Larry was being examined in the outpatient clinic. When the doctors decided to admit him, he began screaming that he didn't want to go into the hospital, and wanted to go home; if need be, he would crawl out in the snow and die. The parents stood behind the decision to admit him. Larry went into the hospital screaming that he wanted to die. Two weeks later, when he was about to be discharged in good health, the intravenous antibiotics having done their job, I said to him, "Larry, you remember what happened when you come into the hospital, you were saying you want to die?" He smiled and said, "Yes, but only if I can't get better." And so in all of the patients we are hearing about, I don't think it's really possible to make global statements. I hate to use the trite phrase of team work, as Dr. van Eys mentioned, but the critical thing is to have a group of people who work together, know each other, and trust each other's judgement. Then you are in an excellent position to approach the patient as an individual and deal with that patient properly.

Dr. Christ

I wonder if that isn't slightly begging the question that was raised: Is there a developmental point at which a youngster can make a decision of that kind. I was thinking about that, and decided that the age at which you can make a decision of that kind is 52 years, so that today I feel that I could make that decision (laughter). Seriously, though, the reason I am teasing about that is that it is such a subjective thing. We can talk about Piaget's states of cognitive development. We can talk about a child needing to be at the concrete operational stage in order to, at least, have the cognitive capacity to know whether death is reversible or not reversible before he could responsibly sign a consent form. But I wonder if there is not another point behind your question: I think you pointed out that there are three different independent judgements, hence decisions that can be formed, one by the patient, one by the family, and finally, the one by the treating staff?

Dr. van Eys

Can a patient, no matter the age legally, socially, and medically, make a judgement that this is the end and cease treatment? Legally, the answer is no below a certain age, unless the court helps the patient to make that decision. Socially, it is very hard to do. Medically, there will always be a difference of opinion. The point is, however, that every child decides sometime or another that he is dying. Nobody else can make that decision for the patient, nor can one talk the patient out of it. And it is almost invariably correct. I have never heard a child say that I am dying at a time other than when it is medically true, unless the child is overtly suicidal. To say that I am dying is vastly different statement from saying, "I don't want any more therapy." Then you have to start thinking about the semantics of "I don't want any more therapy." Does it perhaps mean, I don't want any more needles; or, I don't want this, or that? The statement, "I am dying" is frequently heard, seen in drawings, or given to you in gestures as long as you are sensitive to it.

Dr. Flomenhaft

How do you reconcile the child's feelings with the wishes of the family?

Dr. van Eys

By that time, there is no way under God's green earth you are going to salvage that patient. His perception is usually correct. He is dying.

Dr. Flomenhaft

And you will share that with the family?

Dr. van Eys

It is true that the family, very often, is the last to hear. I have often told the anecdote about the little boy who was trying to tell everybody that he was dying, and nobody wanted to hear. Finally, he said it out loud to a resident who was changing his intravenous bottle, "I know I am going to die." He did die, then and there. I have never seen as shaken a resident as this person was. But the boy had been trying to tell everybody, including the child psychiatrist, for 14 days that he was dying, and nobody wanted to hear him.

V. REFERRAL TO COMMUNITY RESOURCES

Phyllis Cohen - Social Worker, Brooklyn Center for Families in Crisis and Jewish Board of Families and Children Services

I have a question for Mrs. Christ. In your points around crisis, I was struck by the issue of separation at the first point of termination when the patient returns to the community. I am curious about the referral to outpatient mental health facilities at that point. Whether or not you find that the patient is able to make the separation from your institution to another group of treating professionals, and the receptiveness, on the other hand, of the professionals in the outpatient service.

Mrs. Christ

It's a good question which we ponder over a great deal. We wish referrals to other mental health facilites were more possible than they currently are, especially as kids are living longer. We are having more long term survivors who do have long term developmental adjustment issues which may be effectively addressed away from the cancer center. We would like to be able to refer them to outside mental health or family service agencies. At Sloan-Kettering, the social work department has had some family service agency staffs go through a training program to learn what cancer is all about.

Referral has been a problem. You refer a patient to a mental health clinic or family service agency and they say, "We can't take this patient because the person is sick. The individual has cancer and we don't know how to treat that." These staffs don't really understand the psychodynamic and interpersonal issues in-

volved in helping a patient adjust to having cancer, living with it, or being cured of it. One possible way of dealing with the referral problem is a massive or at least an increased educational program for mental health and family service agencies which could possibly take some of the burden off of us for some of these problems. These are long term adjustment problems which do need at least once or twice a week intervention in order to help people to function optimally. It's been a problem as you well know. Anyone who has worked in a cancer center knows what it is like to try and refer someone out and be told that they have cancer, hence they cannot be seen for emotional counselling in the other agency. It is certainly a problem we need to address. The challenge is: How can mental health professionals be educated as to what the issues are at each of the crisis points including the long term survivor crisis points which Dr. Koocher addressed?

VI. EXPERIMENTAL TREATMENTS

Candace Erickson - Director of Behavioral Pediatrics at Baby's Hospital, Columbia Presbyterian

I have a question for Dr. Miller. You were talking about the difficulties with parents accepting experimental treatment. At Baby's Hospital, I find that our residents have a lot of difficulty with what they have to do with patients, administer drugs and doing tests on these kids when the kids are dying. A lot of the residents' uncertainty and uneasiness are being transmitted to the families, the parents and other people involved with the child's care. I was wondering what your experience has been with this? And how do you help the residents who are actually doing the front line care in these situations to deal with their own emotional reactions?

Dr. Miller

This is a tremendous problem. In our center, the resident staff has a major role providing primary medical care for the patients on the inpatient service, that is fluid and electrolytes, writing antibiotic orders and making sure that input and output are reasonably balanced and that vital signs are okay. But obtaining informed consent, discussing the treatment protocols, particularly if it involves experimental chemotherapy, are the responsibility of the very senior person, primarily the person who is the most involved with the family; or those individuals working with the experimental chemotherapy service, who are very familiar with the treatment protocol. They can explain to the nursing staff and the resident staff the rationale, the required laboratory studies, and the special procedures that are necessary before a patient is enrolled.

We are relying less and less upon our resident staff for the day-to-day outpatient management of our patients. Our attending staff is now very directly involved in providing primary care for outpatients. In fact, we have elective residents in our clinic, who work in a preceptorship with an attending physician. The primary health care delivery team is composed of senior attending and a nurse practitioner. We are trying to get away from the discontinuity of residents providing health care for patients. The resident staff has problems because they don't want to get too involved in things. They like a thin chart and don't want a lot of complications in patients, but would prefer to have life very simple. Residents don't want to take care of very sick patients and are a little bit frightened because of their own insecurity about dealing with a chronically ill child who is a month away from dying. They deal with patients who have a fatal disease and are at the end stages of the disease in the following way: "Let's not go on with life", "Let's make sure he has a nice quality of life"; and, then "Let's not pursue all of these crazy chemotherapeutic agents for the sake of science."

We hold his hand to make him understand that we have a grave responsibility in prolonging the life of all children with cancer by looking at experimental chemotherapeutic agents. But we really don't ask him to get the informed consent from the family.

Audience Member

What happens in my hospital is that the residents are doing the day-to-day management, drawing bloods, conducting the studies and, finally, the child leaves the hospital full with these drugs. The residents are very upset about their role in the treatment because they don't see the value of it for the individual child. They really, in a way, become the child's advocate. In turn, the parents pick up a lot of the residents' uncertainty and, therefore, start questioning the medical treatment.

VII. STRESS POINTS

Dr. Miller

I just wanted to pursue a question raised in Mrs. Christ's and Dr. Koocher's paper. When is the most stressful time experienced by a family? Dr. Koocher spoke of the time at diagnosis as being so stressful that families experience shock, dismay, and total numbness. With the improving prognosis in childhood cancer and general optimism, we have noticed that maximum stress and shock are not at the time of diagnosis, but at the first relapse. At the time of diagnosis we tell the families that if it's ALL, your child has anywhere from a fifty to a ninety percent chance

of survival. We are now talking about greatly increased chances of survival for some selected subsets of patients. The families then ask what happens if my child has a relapse? After bone marrow relapse for a child with ALL on therapy, the time of survival is only about eight months. The number of long term survivors after a bone marrow relapse on therapy is less than ten percent, possibly a bit better if we can perform a bone marrow transplant. The families are aware of these figures and the implications of recurrent disease while their child is on the most effective and best available therapy. We find that the time of relapse is when stresses and strains are maximal. Perhaps we emphasize the optimistic aspect too much during the early stages of the disease, so we see a much stronger stress response at relapse. This is the point in time when the team needs to be mobilized to support the family.

Dr. Christ

Would you like to clarify that? Are you talking only about experiences with survivors or also nonsurvivors, with good or also bad prognosis cancer?

Dr. Miller

I would say that the same is true for most of the tumors that we treat today.

Dr. Christ

I was wondering whether the point of death might be an even greater stress point? It's more than just a moot point, because of the related question of when to mobilize whatever clinical resources are available to work with families. If resources are limited, when do you work with the families?

Dr. van Eys

I think the basic difference between the first relapse and death is that the first relapse is relatively unexpected, comes suddenly, and is hard to prepare for, while death is almost invariably thought about. It is easier to anticipate the stress of death than it is to anticipate the first relapse. I would like now to make a general comment about the nature of our discussions. I see and hear no distinction made between cancer as defined by the experience, and cancer as defined by some objective biological phenomenon. Somehow or other, we always mix those two up. The fact of the matter is that the biological phenomenon of cancer is an extremely hard diagnosis to make. The M.D. Anderson Cancer Hospital is referred more diagnostic questions than any other institution, except the Armed Forces Institute of Pathology. More often we say, "No, the patient does not have cancer", than we say,

"Yes, the patient does indeed have cancer." The problem is that we create an emotional climate of cancer. This whole push for early diagnosis created in many strong feelings about cancer. When we said that early diagnosis was a life saving device, in reality most of those people either would never have had cancer or, if they did, it would never have bothered them. We have to be extremely careful because those psychosomatic and psychosocial relationships to cancer connect cancer the experience to human events, while in reality, it has to be cancer, the biological phenomenon, that you have to deal with.

Judith Ingram - Social Worker, Sick Children Hospital, Toronto, Canada

I have a collection of questions for Mrs. Christ. Given the limited staff resources in a social work department, at which of the stages outlined is it most important to offer social work help and support in counselling? My second question is, within the framework you outlined, at which phase might one usefully offer a group, rather than or in addition to, individual counselling? Do you think that there are phases when the group experience would be counter-productive for the parents and the children? The third question relates to parents who have to cope with both the diagnosis of cancer in one child and say the birth of a new baby concurrently. I have had three of these parental situations in the last few months. I have had one French mother reflect on her own difficulty in feeling close to the new baby. She says that she plays less with the new one, she sings less with the new one, and she really is very much aware of having difficulty in bonding. I have got an English mother who had more than usual difficulty in getting herself into hospital to see her newly diagnosed child, and she stayed home with the new infant. And I have another mother who seems to be able to cope fine. However, these others are high risk situations to which we should be especially alert.

Mrs. Christ

I would like to start by commenting on the question of other populations at risk. It is true for the parent of a child who has cancer, an ordinary life stress like giving birth can become an extraordinary stress which does require intervention. The sudden diagnosis of the grandparent with cancer while the grandchild is under treatment can become an extraordinary stress for the parent. There are a number of other life stresses which under normal circumstances would be managed well, but because of the accumulation, the stresses of the child are managed poorly. My staff is very familiar with this phenomenon and often receive referrals at this point.

In reference to the question on staff resources, the reality

is that if you open the case at diagnosis, you remain with the case through all the stages of treatment. If you have a vulnerable family, you will need to recognize the areas to be investigated, to define the tasks of intervention, and to set realistic time limits on your intervention. Essentially, you must be involved at the terminal phase when most families do require more intervention time. One of the problems gets to be that workers do spend an awful lot of time with patients during this phase, and forget that families are having stress at the other crisis points. In order to resolve the problem of limited staff resources, you intervene only at the end points. In my opinion, that is not optimal. Certainly, the pathological and the vulnerable families should be monitored at all eight crisis points. One of the realistic problems which we have is that if you open the case, they are yours, and they will come back to you. It's very hard to turn a mother away when she is in tears and is at your door.

Now I would like to comment on the referral question when cases are not opened at the time of diagnosis. Our social work referrals come through the multidisciplinary team meetings attended by nursing and medical staff as well as by social work observation. The whole mental health team makes a decision about what to do about behavioral symptoms which have been observed by any member of the team. Additionally, the team meetings are often a good time to make appropriate assignment of personnel. Interestingly, patients and parents will often refer themselves.

In reference to the use of groups, the social work department at Memorial Sloan-Kettering is very group oriented, conducting about forty-five groups throughout the hospital. In Pediatrics, we have an adolescent outpatient group, a parent outpatient group, a family group on the inpatient service, a children's play therapy group primarily for latency and pre-latency children. A monthly parents group is conducted by Dr. Miller. A group experience is enormously helpful for these families.

I don't think there is any time when a group experience is counter-productive. There are always some families who are unwilling to participate in group and would prefer an individual experience. These individuals will select themselves out of the group at any point. Usually, people will be more hesitant than they need to be about participating in a group, so I think most families, children, and adolescents need to be encouraged to participate, at least to try it, and see if they can get some benefit out of it. If they don't like it, they will bow out.

Ms. Adams

I agree that mothers who are pregnant at the time the child is diagnosed are at a greater risk on their forming and antici-

pating new life. Suddenly they are dealing with a tremendously stressful situation in the hosptial. The problem arises when the baby is being born at the same time that the other child is being diagnosed and as yet the social worker doesn't have a relationship with the mother to work with her around all of this. The mother may already be in the hospital for the delivery. Sometimes, when the diagnosis is made and the baby is not due for a few more weeks, the social worker can get to know the mother and anticipate with her what she would like to have happen. A philosophical point in my work is that I try very much to approach families with the assumption that somehow they have managed life so far, and my job now is to help them continue to do that as they have, and to focus on their competence as parents, and to find ways to help them continue to feel competent. So I will always ask, how would you like this to go? What would you like to have us do to help you? Mothers need permission to not be at the hospital, if they really would prefer to be at home, and not feel guilty about the decision. I also have concern for the fears and fantasies of the child, who is the patient. It's not unusual in my work with a child to find that they think their mother has gone off to a hospital to get a baby, and so she has traded them in to us in exchange. I have come across this many times and it does not reflect any pathology in the family, but the normal reaction of an average four year old child who tries to find a reason why all this could have happened to him. The reason which he comes up with is that his mother has found someone to replace him, so she has traded him in. I find it very important to work directly with the child about this. And to work with other responsible family members including father, grandmother, and so on, to help them identify the mother to be a stable figure for the hospitalized child, and to allow the mother to do what she feels is best and support her in it.

VIII. CROSS-CULTURAL FACTORS

Risa Boyers-Nadel - Sloan Kettering Cancer Center

I wanted to address my question to Drs. Flomenhaft and Martinson. I agree that cross cultural factors play a large role in the way families reach out to and utilize health care services. However, I think that healing is more than a social activity as Dr. Flomenhaft described it, because it takes into account larger legal and ethical issues, such as those of informed consent and decisions from court cases like those involving Jehovah Witnesses. I was wondering if you found any differences in the legal and ethical issues, and how these impacted on the overall cross cultural differences?

Dr. Flomenhaft

I did not, but I think you are raising a very important question that prompts me to want to run to the library or to visit some other country. These legal and ethical issues are important. Possibly, Dr. Martinson who was in China can relate to your question.

Dr. Martinson

It was these issues which I found quite hard in my experience at the University of Minnesota, when everyone knew the child was at end-stage and yet we kept the child on one more protocol. At times, we had over treated because we weren't quite ready to accept that the time to stop this cure orientation had been reached. This was supported by the autopsy reports which showed that some of these children had been treated extensively. I went from that type of experience to another culture where children who could live normal lives were not, because of limited financial resources. It was hard for me to see how at times we spend so much in this country on very ill people, whereas in these less developed countries, a small expenditure of funds could save so many lives.

Dr. Flomenhaft

Possibly, legal issues develop out of a much more open society. The cultural groups described in my paper have a great deal of reverence for and dependence upon the physician. There is little questioning of the physician's authority. Contrastingly, in our country among many cultural groups, patients feel that they have many more rights. As we know, physicians have been faced with malpractice suits, a phenomenon unknown in many countries. It's part of a larger cultural context that you have to consider in relation to legal and ethical issues.

Dr. Jayakar

I would like to pick up on the cross-cultural factors. I remember a statement made about me by a referring physician to a patient that if I the doctor were Indian (Asian), would that make a difference to the patient who was of a different cultural background? The patient remarked that if you think she can treat me, then it is okay with me. That was an important issue to come up, whether cultural differences between physician and patient interfered with an ability to understand the patient.

The second piece relates to punishment and the Indian culture. One of the major reasons that Indian parents withdraw from treatment and fail to go all the way through, in spite of being given assurances of possible cure or long term survival, is the fatalistic

attitude that God has given this illness, and this is the way one has to deal with it, and one should not fight it. Not merely because it will bring on punishment, but because it's not fair to the child and it's not right. Clearly, the cultural background of the patient has to be understood.

Noel Griffis - Nurse Adolescent Care, Montefiore Hospital, New York

I would like to add a little information. I am part American Indian and part Irish. I don't look it at all. However, I was brought up as an American Indian and may look at things differently than many of you in this room. To be brought up American Indian means that you are not supposed to tell anybody that you are ill; you are not supposed to tell anybody that you don't feel good; you cannot cry, and it's a really hard thing to deal with. I was also brought up by an Irish mother who was taught the same way in a convent. It has been a difficult life because I have learned to cry but it's hard.

I remember when I studied maternity, that the Asian mothers would not cry, would not scream, and would not say a word during delivery. How many of you when giving birth can remember that feeling of pain? And then, if you studied the Spanish woman, she would scream before and during delivery. I love my nursing background and education because we studied a lot of cultural differences which threw a lot of light on the subject. My whole class was a mixture including ten Jewish girls, four Irish girls, and Spanish and Black girls. We had everything. It was such a great class because everybody shared all these differences which are so important when dealing with kids.

I am caring for an asthmatic child who I can see is not breathing. But he is not supposed to tell me about it because he could get in trouble with his family. Or I have a sickler (sickle cell anemia) who was taught not to cry and is holding back all the pain. If I don't come and say, "Look, I have to give you a shot because I see you are in pain", then I feel wrong. I don't know if I am supposed to stop their pain or not. I get caught up in my feelings and wonder, am I supposed to stop their pain? They get mad at me sometimes; I can almost hear the patients say, "I am supposed to be in pain; I am supposed to be able to hold back; I am supposed to be able to take it all." I don't know if I am forcing myself to take away their pain and if it's good or bad. Those are hard feelings which we are going to be hearing more and more, especially in New York, California and Texas where there are people from so many different cultural backgrounds. These different groups are spreading all around the country. I get torn sometimes to think that I am forcing myself on somebody when realizing that a lot of people do not express pain.

IX. HOME DEATH STUDY

Dr. Elaine Miller - National Cancer Institute

I would like to ask Dr. Martinson some practical questions. In the study you presented, were you using volunteers? We are training volunteers to work with the nurses. Are your nurses part-time? Are they hospital based? These are just ordinary housekeeping questions, but they are important for us. Finally, what do you see as differences between hospice care for adults and for children?

Dr. Martinson

By the way, it was the National Cancer Institute that funded the study I presented, so I am glad that you are able to hear the results. Please let me take the question on volunteers first. I would urge that you train volunteers whom the family would identify. I found with these families that it's hard enough just getting one person, one health professional, in the home. The families have a lot of stress. Many of the family members said that they found even their neighbors almost troublesome. For example, when a neighbor brings over a hot dish, that meant the family would have to give a whole hour to talk to this neighbor. They do not have the time and the energy for that. So one needs to be very cautious with volunteers, especially for children. I think having the family identify specific and concrete tasks for the volunteers are generally beneficial. Frequently, these mothers and fathers said that to have somebody call up and ask, "What do you want me to do?" tied them in knots. Instead, what that volunteer would like to do is more useful. The parents tend to worry about it and so it's much better to have a specific task in mind. Can I bring a hot dish Friday night? Not can I go grocery shopping for you, but what do you need from the grocery store? Or else the other way to go would be to offer to teach volunteers whom the family has picked out. In this regard, a difference between hospice care for children versus adults is that parents give care until they suddenly panic. For that reason, we try to get back to the family within five minutes of their call for help. Adults in hospice care tend to call before the crisis point is reached.

We used a wide variety of nurses, including those working as public health nurses in rural areas or as hospital nurses. This project work was an add-on to their regular job. There was only one time that the project interfered with their regular job. I really got in trouble then. One of our faculty members was caring for a child when she had to leave her nursing students on the station. Wouldn't you know, I got called into the Dean's office on this. It happened very infrequently that you had to be called away. Nevertheless, arrangements need to be made with both public health nursing and the hospital that these are priority calls. If

the family wished that nurse to come, she could leave the station immediately, but it never did happen. The only time it happened was with that faculty person.

We did develop a nurses manual and a parent manual. The latter has actually been much better received. That was quite an experience, to put down in writing a manual to give parents! Also, we made a 22 minute film whose reviews have been pretty good. For further information on the manual and the film, write to me at the Home Care Research Fund, University of Minnesota.

Audience Member

Did the nurses get pay?

Dr. Martinson

I paid them a flat $10 an hour, which opened up for me a whole different way of thinking about this health care system. We could employ a lot of local nurses in our communities, if we could work out some way of a direct reimbursement to nursing. Presently, our own University Home Care Department is having them charge $60 for the nurses to make an injection in the home. The nurse is only going to be paid $7. We would be further ahead to utilize the nurse who lives right next door and pay her $10 an hour. This is what I am into now, trying to develop a sort of block concept of nursing that would really help us in our rural areas in this country. In Minnesota, we really have a lot of rural areas. In New York, I know you have problems, but you have people who are much closer together here. It's a little bit harder when people live 500 miles apart.

Dr. Allan Hurst - Downstate Medical Center, Physician Liaison Medical Service

I just want to make a comment and then ask a quick question. We use methadone with adult patients. We have had very good results, but the people who felt the most concern about the use of methadone were the families of the patients and the staff. If you are using methadone, I think you have to speak to the family and staff.

Dr. Martinson

Was that because of methadone being associated with drug addiction programs?

Dr. Hurst

Yes, there was this connotation and the family felt very un-

comfortable with the use of methadone, even though the patients did much better than with other types of pain medication. It was a bit of problem even where it was clearly the better approach.

Dr. Martinson

It's nice to be in such a place. We are not that sophisticated in Minnesota.

Dr. Hurst

Second thing I wanted to ask: You reported 53 percent of the people as not having any difficulty dealing with grief. I am just wondering how you felt about the accuracy of that large figure?

Dr. Martinson

You could come and read the interview data. The parents were really back functioning in their jobs. They had not lost any work. They were back with their friends, back to their normal way of life. These were some of the major criteria that were used by the panel. Certainly, not totally free of problems, but they were back sleeping at night and weren't having illnesses. I was really surprised; I had not expected that. But the parents even rated themselves better than that.

Dr. Jayakar - Downstate Medical Center

The physicians were primary physicians. There were 23 different ones who were primarily involved, who made the referral and knew the most about the child. In other words, I think it is a very interesting model in contrast to hospice programs which have a medical director. We did not go into that at all. This program was nurse directed and used the patient's own physician to handle the medical management. I think that the way to provide better medical care is to involve the primary physician who knows that patient and family best. Were all these children off treatment in terms of chemotherapy? Had the parents made the decision to stop?

Dr. Martinson

No, some of the chemotherapy drugs really helped symptom control. When I started the study, I thought it would be nice and clean and the children would be all off of drugs, but that is just not the reality of the world. I really did depend on the physician saying "You know, this is really it." If the physician wished to maintain some of the chemotherapy drugs for symptom control, it was done with a very clear understanding on everyone's part. In fact, in the beginning of the study, I thought that's where the problem

would be, because in a four year period when I was doing voluntary work in this area, I got a total of eight referrals. The first year I was funded by NCI, I had 32 referrals from physicians in one year. I think several things went on. Physicians became aware of what I was trying to do. Initially, during the early years of my work, the physicians felt that I had made them think of difficult things. Now they felt there was an option that they never had before, and they could be more realistic and more honest in their perception of this patient's care. Those were the benefits that came out, so that I really ended with excellent relationships with physicians.

X. CANCER VERSUS OTHER TERMINAL ILLNESSES

Mr. Roger Parker

I just want to add something that might be a bit controversial. One of the striking things in conferences about cancer, including this one, is that people who work in the cancer area are preoccupied with death and dying. We all come from a society in which we are really interested in our own immortality or mortality, and deal with death on a range from denial to preoccupation. With that as a given, we follow in society's footsteps in reference to societal values and norms around cancer. Putting yesterday's proceedings into perspective, I must note that out of every five people who die this year, only one of those individuals will die of cancer. Two will die with cardiovascular disease, but yet if we were at a conference on cardiovascular disease, I doubt if there would be as much activity, time and interest spent on the subject of death and dying. Frequently, I find it's not that people don't have permission to cry or to express sadness or grief, but patients and staff will struggle with lack of permission to feel good. Is it okay for people to laugh, to joke, to find happy things, and things to feel good about in the experience? Is it okay for a nurse to say, for instance, "I am working with cancer patients, a number of whom die, and I really feel good about the kind of work I do?" I get my batteries recharged from the positive experience. We don't do this because we are socialized to suffer.

Dr. Flomenhaft

What do you think is the difference between those two diseases?

Mr. Parker

Society is reacting to the fact that the word cancer is highly positively correlated with the word death which influences the values and norms in our society.

Noel Griffis

A number of people in my own immediate and extended family have died. There is a big difference between somebody dying suddenly and somebody dying slowly. I have a girl friend who took care of her dying father for two years, and it took a lot more out of her than me when my mother dropped dead on me one night. You have to learn how to live with somebody dying slowly. We are just learning to do that in the United States, I am sorry to say. People have been dying all of our lives, but nobody ever said anything about it until fairly recently. Everybody was always afraid to say it, but there is a difference between somebody dying spontaneously fast and somebody dying slowly. We are just trying to learn to work out the difference in the two situations and to help other people deal with it. Nobody has been willing to help people deal with it before.

Dr. Miller

I would like to pose this question for the panel and the audience. How often have family members and rather close friends asked you how can you stand what you are doing?

Dr. Flomenhaft

Do they ask you that question?

Dr. Miller

All the time. Yet when I try to say that sixty percent of the patients whom I am taking care of have a chance of being cured, in contrast to other areas in medicine today where the prognosis is not that good, people still don't seem to understand that we are in the frontier of a very exciting field. The advances that have been made in childhood cancer are truly remarkable. It doesn't mean that we should become complacent today, and say that the battle has been won. But it is certainly a very exciting field of medicine to be in today and one that shouldn't really depress us.

Brenda Traynor - Nurse, Memorial Sloan-Kettering

I think there is a big difference in people dying from cardiovascular illness and cancer for the nurses and doctors who work with these patients. Is it more the child dying or the pain and the suffering which the child and the family are going through which affect the health care team? Is the team more affected by a child who dies very suddenly or by someone who is lingering for months and months and in so much pain and you can't control it?

Dr. Christ

What you were describing reminds me of the difference between the cancer team on the one hand, and say a team that might be working with severe burns. I suspect the type and intensity of pain with a severe burn might be much greater than with most cancers. I wonder if anybody here has had experience with that group in contrast to the cancer group as a way of answering your question?

Dr. Koocher

There are three factors which have clearly been related to reducing your chances of burnout and job stress. And it doesn't matter whether you are stressed because you are working with cancer patients, because you are an intensive care nurse, because you are working with burn patients, because you are a psychiatrist whose patients are suicidal or chronic. One factor is a supportive work environment where you have a supervisor who can let you take time off when three poeple have died on your shift in the last week, or who recognizes the value of your work and pats you on the back for a valuable contribution. This kind of understanding supportive work environment, regardless of the patient population, is one key factor. The second factor happens to be individual self understanding. If you can recognize in yourself when you are stressed, when you are depressed, and when you have an issue, then you can deal with it. If you don't recognize that in yourself, you are likely to act out or behave in ways which will get you out of that work place either by running away or getting fired. The third factor which will reduce the likelihood of burnout occurring is how you parcel out your life's time. If all of your energy is invested in working with patients who are doing poorly, are highly stressed and in a lot of pain such as burn victims, you are not likely to last. I know a pediatric oncologist who spends a month every summer as a camp doctor working with healthy kids, another one who moonlights in emergency rooms, not because she needs the money, but because she likes to stitch people up and send them home. I know a social worker, who, in addition to doing casework with cancer patients, does supervision, training, and writing. If you experience yourself as a professional person in a variety of spheres, then you can take some wounds and bludgeoning in one sphere without demeaning yourself as a person. These are the critical factors in maintaining your sanity in this type of work.

XI. GROUP INTERVENTIONS

Dr. Miller

Can I make a point about times when the group setting is really not appropriate for discussion on certain issues? We try

to have a general discussion about reactions of family and extended members to the child's diagnosis, and the reentry of the child to the school. Families are particularly supportive of other families whose child's diagnosis was just recently made. But the one area which we try to skirt in the parent group meeting is specific details about a child's medical therapy or a change in status. Instead, we try to discuss generally and provide educational and informational material about treatment. Rather, when it comes to the specific details of the child's status, we try really to have a one-on-one meeting with the mother, the father and the social work and medical staff who are supporting the child. It gets a little bit hairy sometimes to try to get into those details and usually they are picked up after the meeting. We try to avoid that kind of very personal concern about why is Johnny not doing well and what is his bone marrow like. The group setting is not the format for this kind of discussion.

Mrs. Christ

Those are specific issues which can come up anytime. But even for a family where the patient is terminal the family group can have a very productive exchange, or it can be a time when the family simply does not want to talk about it.

Dr. Martinson

Regarding the use of various treatment modalities, we found with the families post-death is that one-third of the families felt the group experience was helpful; one-third were helped in a one-to-one relationship by a variety of professionals including a social worker, a nurse, a clergyman; and one-third of the families received no counselling. We then compare these family groups on a variety of measures and found no difference among the three groups.

XII. STUDENT TEACHING

Eleanor Lundeen - Nursing Faculty, New York

My question is mostly for Dr. Martinson, but anybody could answer it. What kind of learning experience on the student level have you found to be most effective to enhance their growth and development in dealing with oncology patients?

Dr. Martinson

With undergraduate students at the University of Minnesota School of Nursing, we use a twenty-two minute documentary film on the home care project that stimulates a lot of questions and

discussion. At this time, I do not have undergraduate students or even master students working with me because of the large distances covered by the project. However, from the time of diagnosis some of the nursing students are becoming involved and follow families. Hopefully, the follow-up will be for several years because cancer is becoming a chronic disease. By entering the case at the very beginning, the student would have an extremely powerful learning experience and excellent preparation for future work.

Dr. Flomenhaft

Would any of the other disciplines care to address the issue of training?

Dr. Koocher

One important area which I would definitely ask of job applicants working with this population is, "Tell me how you have handled loss experiences in your life." I learned that too late after hiring a female psychology intern who wanted to do an oncology rotation. We had arranged that when the training year was up, I would pick up on the intern's five year old oncology patient on whom I was supervising her. Although we had talked about termination and transfer issues for two months prior to the intern's departure, I discovered after she had left that she had not told the patient that she was leaving. Two months later, in response to my nasty letter, she telephoned me to talk about it and offered the following statement: "Whenever I have been faced with a loss or rejection in my life, I end the relationship by leaving abruptly to avoid being hurt." Essentially this is what she was acting out. The trainee who can talk with some insight about his/her own coping with loss and recognize those issues will be far better able to deal with these patients.

Mrs. Christ

I would support what Dr. Koocher is saying that there are just some students who have particular difficulty in dealing with loss and do not do well in our setting. We try to do some pre-screening with our social work students, but it is not always possible. Some of the students drop out of the hospital after a couple of months. No matter how much support is provided, they just don't make it. There is a student support group which spends a lot of time on the initial impact of the institution and working with the physically and terminally ill. The institution has to provide a lot of support to enable those who are capable to be sustained during the training period. Nevertheless, there are some people who can't do it because of personal problems or issues in their own personality and character makeup. I have the same impression about the other

disciplines in our hospital, that there are trainees who just cannot do the work. They leave after a few months, especially if you do not provide institutional support for them.

Brenda Traynor - Nurse, Memorial Sloan Kettering

I just wanted to comment on the earlier question about students and training in our cancer institute. I am a recent graduate of Downstate Medical Center. I did my final ten week student rotation on pediatrics at Sloan Kettering, which helped me very much. At first, when you go into nursing, there is so much to learn that the idea of oncology gets pushed into the background, or it gets all clogged together and you go nuts. Those ten weeks which I spent on the floor helped me to see all the stresses, the way they affected me and to start dealing with them before I started work as an R.N. on the floor. This student experience was invaluable preparation.

XIII. STAFF ROLE OVERLAP

Betsy Fife - Psychiatric Nurse-Clinical Specialist, Riley Hospital, Indianapolis

I have a question for Dr. van Eys. When you were presenting about the role of the different team members, distinguishing very clearly between what each individual did, how do you handle the overlap of the psychosocial types of intervention when each professional person is concerned with the holistic approach to care?

Dr. van Eys

There is an enormous difference between the interaction of a professional, a patient, and a family on a person-to-person level and on the ward or in the clinic. Every person is hired because they have expertise that somebody else does not have. I respect that special body of knowledge. Even though I might consider myself an amateur psychologist, I just am not. Therefore, I ought not to meddle in that area at a professional level. The problem we always get into is that people confuse their importance within the team on the basis of the degree of friendship extended by the patient to them, rather than the degree of need which they should have for that special knowledge. So the nurses compete with the social worker for the friendship of the patient rather than for their special knowledge. Surely, I have enough to do as a doctor, not to want to be a nurse. This is what you have to distinguish. There are two rules which help me. The first is that our hospital is indeed an upbeat place and our work emphasis is on cure. Therefore, I honestly think that forty-five groups are just too many to deal with. Then you start worrying about the badness rather than

thinking that it's a pretty good place to work. It's a rather pleasant place. And the second thing is, don't take yourself so seriously.

Ms. Fife

Is this something that you talk about occasionally on an individual case basis, or is it something that you sat down and worked out as a team?

Dr. van Eys

Yes and Yes. I have been known to take some of my younger doctors for lunch.

XIV. PARENTS AND SIBLINGS

Marilyn Dwyer - Nurse, Memorial Sloan Kettering

Once in a while on the floor, we'll have a teenager act as the parent substitute because the parent might be an alcoholic. For one reason or another, the parent is unable to stay with the sick child. Has there been any study on the long term effect on the child who acts as the parent substitute for the sibling who's dying?

Dr. Koocher

I know of no such study. The only analogy I would make is where the family experiences a death and the surviving mother says to the son, "You are my little man now," or the father says to the daughter, "You are daddy's little wife now." Obvious issues are the stresses and pseudo-maturity which are forced on someone who may or may not be able to handle it. It behooves the staff in this situation to try and see what sort of special support the adolescent caretaker might need, and to be clear whether this is something that needs to be pointed out to the parent.

Mrs. Christ

The family so described is obviously one we would define as vulnerable. Sometimes siblings are not parent substitutes but may be substituting some of the times for some of the functions of the parent. This is a discrimination which has to be made, whether the siblings are really taking the place of the parent and taking over too much, or whether they are really assisting the parent. The opposite extreme is when the siblings are excluded from the caretaking situation entirely. Many siblings have reported feeling devastated after the death of the sibling when they felt that

they had no role to play and weren't able to be helpful in any way. A careful discrimination has to be made between when it's pathological and when it's really part of an adaptive coping process.

Dr. van Eys

I would like to comment the opposite of what you just said. We have some trouble with our nursing staff in getting them not to heap guilt on the family member who doesn't stay with the child. It may be realistic for a mother of nine children to leave the one sick life to excellent care in the hospital, and to take care of her other eight, who would otherwise be abandoned. In that kind of a setting, siblings naturally take care of the younger child. It may actually be a natural stage for a particular culture or family. Let's be careful not to be too judgmental on that issue.

XV. PSYCHOSOCIAL RESEARCH FUTURE

Dr. Miller

There are three areas of psychosocial research that we should be getting into with the improved outlook of childhood cancer. For instance, we really haven't looked yet at the effect of developmental chemotherapy and experimental chemotherapy on families, particularly, when one family member wants to pursue and the other would like to stop treatment. A second area that we haven't assessed is the impact of bone marrow donation on the donor. We are now doing a hundred transplants a year at Memorial Sloan Kettering. At cancer treatment centers throughout the country, larger and larger numbers of patients are now being salvaged with bone marrow transplants. But we haven't looked at the donors; particularly, if the recipient of the transplant develops graft versus host disease; the marrow doesn't take and the patient succumbs; or, if the patient develops an interstitial pneumonia and there is a recurrence of the leukemia. We have previously asked the family to participate and be supportive, but we have never before asked the families to donate parts of their bodies in the treatment of childhood cancer. It's going to be very interesting to begin to evaluate that group of children. A third area that is very difficult because no one wants to talk about the child at the end stage of disease is the financial impact of all this on the family. There is the ambivalence of continuing the tremendous financial burden for who knows what kind of an effect. Families don't want to talk about it, but it's just under the surface. It's a grave problem which we really haven't been able to deal with too well. These are just three examples. I suspect that we are going to see many new areas of psychosocial research. Perhaps you can invite us back in a year or two to present them.

Dr. Flomenhaft

Only if all of you agree to come back.

Elaine Miller - National Cancer Institute

I would like to comment on the fear associated with contracting cancer. Much of the fear may very well come from the publicity in the newspapers where the association of mononeucleosis and EVV virus and Herpes virus and later Hodgkins disease and cervical cancer are highlighted. These are probably very strong associations and the evidence does exist that it may, in fact, have a causal association. But this is what's frightening when people read it in the newspapers. The fear of contact when people draw away from a family where there is cancer may derive from this publicity.

Finally, my question is also an appeal to you. What are the areas in childhood cancer that need to be investigated? What do you think needs to be done? Most of what we have heard at this really excellent conference relates to secondary and tertiary prevention, delimitation of disease and palliative treatment are all critical. But my orientation as an epidemiologist compels me to ask what can we do to prevent cancer and what can we do in terms of primary prevention? We learn a great deal from childhood cancer because of the short latency period that hopefully we can utilize in investigating adult cancer. If you have had any ideas of the kinds of research that should be done, we would welcome your ideas and hearing from you.

Dr. Flomenhaft

This is a fitting question to end our conference.

Mr. Parker

There have been some exciting areas identified in this symposium for potential research. I think the debate we got into about cancer patients having different needs around dying than other patients do, such as the cardiovascular patient, and how staff must work differentially with these different kinds of patients, are areas that would make for very interesting studies. I hope that people go away from this conference feeling challenged by having raised some new questions and coming up with some exciting new research proposals that we can talk about in the coming year.

Dr. Christ

There is one area for research. It has more to do with the causation of psychiatric symptoms rather than of cancer. I think

we are in a position to study elegantly some of the late effects of brain damage in causing symptoms of a cognitive and/or emotional nature. Evaluating ALL patients before CNS treatment, then following them carefully, may help us clarify which symptoms in these youngsters may be related to the brain damage produced by the cranial radiation and intrathecal medication. I am unaware of any other situation which can allow this type of paradigm. Not only would this allow us to plan more precise interventions that could be preventive of emotional disorder in the cancer survivor, but it would greatly increase our knowledge about the interrelationship of brain-cognition-emotion.

Dr. Koocher

The etiological nature of the diseases that are cancer are varied and very complex, as noted by Dr. Fox and others. Even after we develop cures for them, we are still going to have to deal with long term survivors. And if I was going to bet money on anything that would have an important impact, it would be on the prevention of psychopathology among those survivors.

Dr. van Eys

I will say something iconoclastic. No disease has ever been controlled by cure. There is no exception to this statement and cancer will not be an exception either. We have a shibboleth that cancers are many, many diseases. I think their similarity far outweighs their differences. And, therefore, if anything is needed, it is to go back to the laboratory and forget our being so enamored by very expensive treatment development.

Dr. Martinson

I have a final word for the nurses here today. When you run into patient-care difficulties, try to get the data down--write down the many factors present in the situation. For example, how you are feeling when people call you at night. Start to identify what are the factors involved in these complex and demanding care situations. As nurses you are working so many areas in which we need so much more research. Don't get too frustrated because it's difficult right now. But you too have a responsibility to help in developing a body of knowledge.

Mrs. Christ

I would support Dr. Koocher's suggestion about research on long term survivors, and of all families going through this experience, whether the patient survives or does not survive. The whole question of what, where, when, how much, with whom, and who is to give what kind of intervention have not been studied at all.

We have not defined clearly what is optimal psychosocial treatment for which patients, when, how much, etc.

Ms. Adams

Whether or not the patient himself dies of cancer, there are survivors of this experience. These survivors include the siblings, the parents as well as the child who had cancer. We need to develop some way of understanding exactly what we do that helps them, what we do that doesn't help, or, what could be done differently to help more in order to facilitate the long term adjustment of the survivors.

Dr. Fox

Dr. van Eys preempted the first point I was going to make, but let me add a supportive point of view. Epidemiologically, if you look at the incidence of childhood cancer compared to adult cancer, it turns out that there is a very, very tiny proportion of all cancers that reside in the child. If that is so, then what you've got is an exceedingly difficult epidemiological problem. Because the number of cases available is just too small, it would be awfully tough to do epidemiological studies or analyze such data. Therefore, there is far more justification for re-focusing one's efforts on the biology, as Dr. van Eys suggested. I do have one question that you might want to toss around. It has been noted that survival in children with leukemia is considerably greater than that in adults. People have said that the immune functions may be involved up to the age of five years but that's also true for older children. The question is, "Why, after the immune system has almost reached maturity, does one still find the difference?" Maybe some of the biology people can answer that.

Dr. Miller

I would take issue with Dr. van Eys because we are in a very peculiar paradoxical situation where we have effective treatments for many of the cancers that afflict children today. We should not belittle those advances. I am sure that he is not. If we had stayed in the laboratory and didn't look at what we are achieving, we might not be where we are today. We should be grateful for that, even though we don't understand why our therapies are working. Now we have a great obligation to minimize the toxicities of our therapy in those patients who have to be so heavily treated, and pursue biological and molecular-biological studies in these diseases. We need to understand why the therapies affect the patients the way they do, and exactly what's causing them. We have a double effort to continue in the clinic and in the laboratory.

XVI IMAGERY

Michelle Roman - Pediatric Clinical Specialist, John F. Kennedy Hospital, Edison, New Jersey

I have a question for Dr. Koocher. I work in a small community hospital. We had a 14 year old who came in for a diagnosis, and it was ALL. After the biopsy, he had a cardiac arrest and went directly to intensive care. They started the chemotherapy in the unit and a question came up whether imagery with adolescents has any value prior to starting the chemotherapy? I was wondering what your experience is with imagery and children.

Dr. Koocher

Imagery is but one technique. You can use the term imagery, suggestibility, or hypnosis, which was the old term for exactly the same thing which is today called imagery. What will work with one patient may not work with another, but, certainly, those techniques have been described in the literature as being useful with young kids. I wouldn't rule anything out with a four or five year old patient who is reporting a lot of anxieties. Certainly, I would call in a consult from someone who knew the technique.

Dr. Christ

A brief warning! The patient that I showed also had just a very momentary cardiorespiratory arrest. We have to remember that there are side effects (especially late side effects) of all kinds, even if it was just a short arrest.

XVII. FATHERS

Malka Young - Social Worker, Sydney Farber Cancer Institute, Boston, Massachusetts

We have several groups which make psychosocial interventions basically with the mothers, because the fathers don't seem to be really available. The fathers are available at the crisis points noted by Mrs. Christ, at day one conferences or specific conferences, but the whole experience seems to be a mother experience. I am wondering, are fathers being supported in the community or do we need to draw them into the hospital experience? I just want people's impressions and comments.

Dr. Miller

When do you have your group sessions?

Malka Young

In the evenings.

Dr. Miller

And the fathers don't come? Perhaps you shouldn't hold them on Monday nights when it competes with Monday night football.

Dr. Martinson

Now in most medical centers in Minnesota, the father and mother both have to be present when the diagnosis of the disease is given. Fathers did thank us, afterwards, for telling them to stay home from work at the end stage of the disease with their children. The work ethic in Minnesota is very strong for men and it hadn't even entered their consciousness that it was perfectly okay for them to stay home. A couple of times we did work hard to make that possible and the fathers were very grateful afterwards. Interestingly, we audio recorded follow-up family visits after the child died, up to twenty-four months post-death, and the fathers were very often present; but as you listen to the recording, you are more apt to hear the mother's voice. Now that we have followed-up forty families, we could go over the data to determine when, where, and how we were able to get to the fathers. From listening to the audio tapes, we have the fathers present but mostly the mothers are speaking.

Ms. Adams

Similarly, we found that the mothers are at the hospital more, and more often spend their nights at the hospital. In the beginning diagnostic phase, we have better access to the fathers. It is especially important for them to have a chance to question the physician themselves about their concerns. What often happens is that a system of communication develops in which the doctor talks to the mother, and the mother talks to the father. Who knows exactly what the father then comprehends of what the mother understands of what the doctor said? You can't be sure. It is very important that the father knows he has permission to communicate with the doctor himself. We try to encourage this two-way dialogue with the physician. In order to meet with the father, I have to be available for evening meetings. But I think it is really important to get a sense of what this is like for him. What are his concerns? We don't want long term communication problems to develop in the family. Mothers seem to become knowledgeable very quickly, soaking up everything, talking in technical terms about the child's condition where fathers might not know anything about it. Quite easily, the fathers can begin to feel left out, less respected or less competent.

Dr. Flomenhaft

We also need to look at the style of the family where the mother may be the primary care giver. It doesn't mean, because the father doesn t come, that he is not interested.

Mrs. Christ

Again, I don't think you have made an optimal evaluation of any family if you haven't assessed every family member. I do get concerned when one person is constantly absent, always out of the picture, and away from the treatment situation. In the one example I gave, where the father was alcoholic, the family members were hiding him. This was an example of a closed communication process where the father was suffering a great deal, but was unable to get help for his problem. It's critical at some point for every family member to be seen and evaluated.

XVIII. SURVIVORS - RECURRENCE

Grania Ackley - Nurse, Pediatric Intensive Care Unit, New York Hospital

I work primarily with terminally ill children with cancer and other diseases. New York Hospital is a half-way step between the major cancer treatment center at Memorial across the street from us and local hospitals. We are stuck in the middle, so that we get the worst of and the best of it. Our highest stress comes when there is disagreement as to how far to treat, especially when the patient disagrees with the doctor, with the mother, with the father or with the staff; or, when the intern disagrees with the attending physician. We have a chronic problem in this area. I am fascinated by Dr. van Eys' staffing conferences and his hope that if the parents and patient were better informed, we could all come to some kind of an agreement. We quite often end up feeling terrible, because the disagreements are never comfortably resolved. There is a residue of bad feelings. Part of our problems may be that we have interns right out of medical school. I swear to God that I don't know what they are getting taught, but they have never heard of a hospice, pain relief, or support after active therapy is no longer a realistic option to some of the patients.

Dr. van Eys

I did not mean to leave you with the impression that the staffing conference is the sole mode of communication. We do have parents and teenage groups which are conducted in Spanish and English. There are certain topics that parents want to discuss in the presence of other parents, and there are certain topics

they do not want to discuss in the presence of other parents. I have a very fixed rule on the ward that a doctor may not use another mother as an interpreter, except in the most dire emergency, because it is not infrequent that the mothers just do not want to tell each other all the details. They may share their feelings, but not the facts. So the staffing conference is not primarily a communication mode; it is putting the patient in the position of an equal participant.

Dr. Miller

If I may be judgemental, one of the problems is that in some centers, you may not have staff who are really committed to clinical cancer therapy or clinical cancer research. What you have described can result from top level people being somewhat indecisive about what to do. Above all, the staffing conference and miltidisciplinary tumor boards, where people are talking to each other, airing it all out, are a most important way to resolve many of those problems.

Dr. Christ

In psychiatry, we probably are more prone to have that kind of problem than in almost any other field, because the degree of uncertainty that we have in many aspects of treatment and diagnosis of our patients is so great. It comes down to something that Dr. Miller was describing that I would like to take a step further. As a leader, one has to send out very clear messages to staff. One example is, you make a decision, and whatever decision you make, we will all live by. A second message is, as a group we will arrive at a decision, and my role as a leader will be to participate in the discussion as a member, and we will then arrive at a consensus decision. A third message is one which says, as a leader, I am going to make a decision, but before doing so, I would like to get some of your ideas and thoughts, although I will make the final decision. It can be very confusing and demoralizing to staff if they are unclear what the leader expects of them. Obviously, even if you say the third one, there are always staff with authority problems who are going to challenge that, but at that point, the problem becomes clear. I would suspect that in a team situation such as the one described by Dr. van Eys, everybody is clear as to who the leader of that group is, and who makes what kinds of decisions about what kinds of things. Without that I think one would have chaos, or, as Ms. Ackley describes, a residue of bad feelings.

Dr. van Eys

I would like to comment at a slightly different level. When a child has a life-threatening illness, there are all kinds of considerations which enter into the child's and that family's

life. But the one consideration which we haven't really talked about is that it is, in fact, realistic to feel threatened about one's existence. They do have a life-threatening illness, and nobody can guarantee that they will live. It's at that level we need to give our care, to shoulder a burden for them which we are very reluctant to do. As long as we are very optimistic or very pessimistic, we are okay. It is the in between where we fall down. I have seen nurses give beautiful care all the way until the child is terminally ill, by any medical objective standards, but the child has not yet said, "I am dying." And therefore isn't. Then the nurse, invariably, comes to me, "Would I please give an order to resuscitate or not to resuscitate?" This is the eternal question which I always turn right back and say, "Why do you ask that?" The answer is, "I do not want to have the responsibility to have to think about it." And, therefore, we need to be a bit more attuned to the angst of the child, and a bit less to the mechanics. I am very worried when I hear an awful lot of excessive structuring of support rather than a bit of personal plunging into the depth of despair which the child, in fact, experiences.

Dr. Fox

Perhaps, Dr. Koocher can help out with this question, because he mentioned this issue. Dr. Koocher said that five years looks like a milestone because many of his families celebrate the passage of that critical time. Yet the data presented in these papers show that there is a far greater risk of recurrence of disease 15 to 20 years after diagnosis than five years after diagnosis. It seems to me that the medical staff, and from them the psychological and psychiatric staff should be aware of that, and possibly guard against the undue optimism of the parents and family for that five year interval.

Dr. Miller

In childhood cancer, it isn't 10 or 15 years later. Most recurring solid tumors are seen in the first six to 12 months after the initial diagnosis is made. In ALL, if the child has been in complete continuous remission for three years and then goes another three or four years without having recurrent disease, the chance of relapse is less than one percent. If you go from tumor to tumor, you'll see that recurrent disease in childhood cancer is something that occurs early. I don't think you have to worry about recurrent primary tumors 10 or 15 years later. Ten or 15 years later, we worry about a second malignant neoplasm. In our experience, this is very rare, and we worry about the late effects of therapy. If a child has gone five years post diagnosis, that child has a very good chance of being cured.

Dr. Koocher

When I made my statement, I was referring to second malignant neoplasms and organ failures secondary to chemotherapy. You do pose an interesting dilemma. If you talked to oncologists they will tell you that cancer is many different diseases, and the real survival treatment curve is different for every disease. For example, with most lymphomas, you will know at the end of two rather than five years what the real prognosis is in a statistical sense. It used to be five years, so that's what parents will seize on. When we did our study, we also asked the family and the kids routinely, "What do you think your chances are of having cancer again?" A large number of the respondents told us that their chances were much less than average, because they had developed an immunity with all that chemotherapy and radiation. Now that puts us in an interesting bind! Do we as investigators then burst their bubble of adaptive denial and say, "Wrong, you have a tenfold increase risk." No, what we decided to do instead was to say, "We don't know what having had cancer means to you as an individual but you have had powerful drugs and radiation; so just get checkups, if you have symptoms, look into them." In a way, we have not given them full information, but our desire not to do that was an effort to maintain the coping mechanisms which the family and the kids had developed.

Dr. van Eys

I would like to both agree and disagree with Dr. Miller. I agree with the early recurrence statistics. However, I disagree that second malignant neoplasms are rare in the genetic subset. Each childhood cancer has a genetic subset. The incidence of second malignant neoplasms in the genetic subset is 17 percent and rising. The proportion that is genetic is not certain, but can be as high as 40 percent, and is probably much higher than most of us realize. Secondly, I feel that late recurrences are probably not recurrences with second malignant neoplasms of the same type. If the child is prone to get leukemia, it is more likely that the second neoplasms is also leukemia. We do see a rather substantial number of late recurrences now.

Dr. Miller

Has that been your clinical experience at M. D. Anderson Tumor Institute, in terms of 17 percent incidence of second neoplasms?

Dr. van Eys

Yes, 17 percent incidence of second malignant neoplasms in the genetic subset. If you plot with time, extrapolating to about 15 years, the curve is still rising.

Dr. Flomenhaft

I really want to thank the panel and the audience for a most intense and informative two days. Many issues have been raised here. We hope the future will find the answers.

Dr. Christ

We have looked at the past, the present, and a bit more dimly into the future. Massive advances in the prognosis of children with cancer have been made, some extracting a heavy price on the survivor and the family. Psychosocial interventions all along the road from diagnosis through treatment to long term survivors are essential. The family as a unit is gravely stressed, and family supports and interventions are sorely required, not only by the emotionally disturbed, the vulnerable, but also by the emotionally normal. Such interventions cannot be blind, but must be evaluated and their efficacy assessed.

Some questions have been clarified, some answered, many more have emerged as childhood has cancer changed from a death sentence to a disease with hope.

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