

Psychological Aspects of the Management of Adolescents with Malignancy*

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Introduction

The approach to total patient care in a teenager with malignant disease represents one of the greatest challenges to any physician. To bridge the generation gap and communicate in an area of medicine where we cannot always cure, but often only palliate, guide, comfort and listen, is often difficult for we physicians who are so often taught only how to win therapeutic battles.

Malignancy is the leading medical cause of death in the 10–21 year old age group in the United States (Table 1). Leukemia, Hodgkin's disease, bone and brain tumors are the most commonly encountered forms of cancer during this period (Heald, 1960).

Problems involved in management of the adolescent who is undergoing the stress of having a malignant disease added to the inherent physiological and psychological problems of this age group are at times overwhelming. They are not the problems of the pediatrician who deals with an infant or child too young to understand the significance of having cancer and who has not developed a concept of self as it relates to death. Nor are these the problems of the internist who is treating adults who may have lived a full life and developed effective ways of adapting to this particular stress.

The teenager is mature enough to appreciate the implications of his diagnosis and prognosis but in some cases the integration of personality and mechanisms of defense are inadequate.

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TABLE 1*

Death Rates per 100,000 for Males and Females in the 10–4 and 15–19 Year Age Groups in 1960 in Five Categories and in Four Countries

	10–14		15–19	
	Male	Female	Male	Female
Motor Vehicle				
Accidents				
USA	9.9	4.2	51.7	16.0
Netherlands	7.7	3.8	19.9	5.1
Japan	4.8	1.8	21.1	3.4
Venezuela	12.6	2.4	26.2	3.5
Tuberculosis (all forms)				
USA	0.1	0.1	0.3	0.3
Netherlands	—	—	—	0.2
Japan	1.6	2.0	4.4	4.9
Venezuela	2.1	3.3	6.5	8.7
Malignant Neoplasms (all sites)				
USA	6.5	5.7	9.6	5.8
Netherlands	6.4	5.4	10.7	3.8
Japan	4.8	4.0	6.2	5.1
Venezuela	6.2	6.5	7.1	4.5
Suicide & Self-Inflicted Injury				
USA	0.9	0.2	5.6	1.6
Netherlands	0.2	—	2.6	0.9
Japan	0.7	0.4	25.3	22.6
Venezuela	0.5	2.4	7.8	11.2
Cardiovascular Diseases				
USA	2.6	2.6	5.4	4.4
Netherlands	1.3	0.9	3.6	2.2
Japan	5.8	6.1	9.5	9.2
Venezuela	4.5	3.8	10.7	6.7

* From Annual Epidemiological and Vital Statistics. World Health Organization, 1960. Reprinted with permission.

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Advances in surgery, radiation therapy and chemotherapy have resulted in prolonged survival in adolescents with malignancy. In addition, secondary schools are teaching human biology and physiology in depth; two of our patients suspected and made their own diagnosis and went to the doctor for its confirmation. Television medical dramas portray adolescents with cancer. In one evening I saw a movie concerning a student nurse with osteogenic sarcoma in love with the young pathologist who confirmed the diagnosis, followed by a weekly medical drama concerning a journalism student diagnosed and under treatment for Hodgkin's disease. These shows make the public more aware of the cancer problem in teenagers but facts may often be over-dramatized. Parents have asked if they should turn off the television during shows dealing with cancer; I think this has to be individualized with the patient and we should be prepared to answer any questions stimulated by these shows.

These three developments may contribute to the accentuation of the adolescent's problems in coping. Today's adolescents are more knowledgeable about life

and living; they are curious about their disease and ask deeply penetrating questions. They must ask the same questions all other growing adolescents face, yet these questions are related to the framework of their illness: "What shall I tell my friends?" "Can I go to college?" "Will I be able to marry?" "Will I be able to bear children?"

Approximately 376 cancer patients in the 10-21 year age group have been treated and followed at the Denver Children's Hospital (Table 2) and St. Jude Children's Research Hospital (Table 3) over the last 25 years. Data in this paper reflect personal clinical experiences in dealing with this group over the last 6 years at both institutions. In the recently developed Denver Children's Hospital Oncology Center we have been following 69 patients since January 1, 1969. These youngsters are referred from states all over the Rocky Mountain region.

Psychological problems encountered most frequently by adolescents fall into five categories: alteration of self concept, alteration of body image, interpersonal relationships, future plans, and management of death (Moore, Holton and Marten, 1969).

TABLE 2

Malignant Diseases Seen in the 10-21 Year Age Group at Denver Children's Hospital in the Past 24 Years

Diagnosis	Age at Diagnosis						Total
	10-11	12-13	14-15	16-17	18-19	20-21	
Leukemia	31	12	36	2	3	1	85
L.S. to All	5	2	5	1	0	0	13
ALL	11	6	7	0	1	1	26
AML	8	11	11	1	1	0	32
Blast	7	4	3	0	1	0	14
Lymphosarcoma	9	4	4	0	1	0	14
Hodgkin's Disease	5	7	8	4	0	1	25
Reticulum Cell Sarcoma	3	2	1	0	2	0	8
Osteosarcoma	6	4	3	4	0	0	17
Ewing's Sarcoma	3	0	2	2	0	0	7
Rhabdomyosarcoma	0	0	1	0	0	0	1
Fibrosarcoma	1	1	0	0	0	0	2
Neurofibrosarcoma	1	0	0	0	0	0	1
Hemangiosarcoma	1	0	0	0	0	0	1
Wilm's Tumor	3	2	0	0	0	0	5
Neuroblastoma	0	1	1	0	0	0	2
Brain Tumors	4	5	4	0	0	0	13
Adenosarcoma	2	1	1	0	0	0	4
Dysgerminoma	0	0	1	0	0	0	1
Teratoma	0	1	0	0	0	0	1
Melanoma	0	1	0	0	0	0	1
Others	0	2	0	1	0	0	3
Totals	69	42	62	13	5	2	194

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TABLE 3

Malignant diseases seen in the 10-21 year age group at St. Jude Children's Research Hospital in the past 5 years.

Diagnosis:	Age at diagnosis							
	<10	10-11	12-13	14-15	16-17	18-19	20-21	
Leukemia								81
Acute lymphocytic	7	22	13	7	6		(55)	
Acute myelocytic		5	5	8	6		(24)	
Chronic myelocytic		1		1			(2)	
Hodgkin's disease	3	6	1	8	3	2		23
Lymphosarcoma	3	4	4	3	1	1		16
Osteogenic Sarcoma	1	4	1	2	4		1	13
Ewing's Sarcoma	1	3	1	1	1		1	8
Reticulum cell sarcoma		3	2	1	2			8
Rhabdomyosarcoma	1	1	1	2	2	1		8
Wilm's tumor	2	1	1					4
Neurofibrosarcoma		2	2					4
Lymphoepithelioma		4						4
Neuroblastoma	1	2						3
Retinoblastoma	1							1
Other	1	1	4	3				9
	21	59	35	36	25	4	2	182

Alteration of Self-Concept

The teenager's knowledge that he has a disease that medical science does not yet know the true cause of and cannot yet promise a cure for, makes this patient feel he is "different." The immediate concern is not, "Will I die?" but, "How will this disease make me different?" or, "Will I be rejected by my friends?" A feeling of inferiority and loss of self-esteem may even cause the youngster to keep his illness a secret.

A 19-year-old boy with Hodgkin's disease, Stage IIIA, was very upset that he was turned down when he tried to join the Army after being active in high school military programs. He tried another branch without telling the officials he had Hodgkin's disease and his parents intervened.

Clinic visits to receive medication may enhance feelings of inferiority and difference, especially if these patients have symptoms of fatigue, anorexia, malaise or nausea from their disease or treatment.

A physician's son with letters in football and wrestling presented with a painful lump on the medial aspect of his thigh and underwent amputation for osteogenic sarcoma (Fig 1). He was forced to limit his activities for several months, and this "sitting on the bench" was a constant reminder that he was different and perhaps no longer as strong as his teammates. He later resumed his wrestling and taught

mentally retarded children how to swim at Summer Camp.

As soon as youngsters are improved clinically we encourage them to engage in as many of their normal activities as they wish. Physicians must often communicate with teachers, social workers, coaches, employers and other members of the rehabilitation team in order to pave the way for the patient to be treated "like one of the crowd" just as he was prior to the diagnosis of cancer. This is no easy task.

Alteration of Body Image

The adolescent's image of self undergoes rapid change as the body matures (Schonfeld, 1963). Changes in physical appearance secondary to therapy only complicate this physiologic adjustment.

Alopecia may occur from radiation to the skull or various chemotherapeutic drugs and is the most common cause for altered physical appearance (Fig 2). It is often more traumatic than the diagnosis itself. To the girls it means a loss of attractiveness and femininity; to the boys it may mean the loss of sex appeal and virility. They often feel unacceptable and withdrawn from society. Fashion today has made it a bit easier for us to recommend wigs and hair pieces since they are in vogue for both sexes and acceptable to adolescents' peers (Fig 3).

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Radiation dermatitis can be a problem for those with solid tumors. These patients must limit their activities to exclude excessive exposure to sun. The darkened, peeling skin and marking used to outline the radiation port may be embarrassing.

J.C. (Fig 4) represents the multiple problem of an already obese teenager recently diagnosed as Hodgkin's. She is a redhead with extra sensitive skin, and wore high necked dresses to cover up her skin changes.

A much more drastic change of body image occurs in patients who, because of bone tumors, may require an amputation of all or part of a limb. Adsett (1963) states, "Paradoxical as it may seem, the fear of unacceptability and isolation secondary to disfigurement can be a much greater source of anxiety than the fear of death itself or recurrence of cancer. There are some patients who would choose to die rather than to be severely disfigured."

An 18-year-old mother of an 8-month-old infant presented with a mass on her leg that was noted 6 months before and initially thought to be bursitis. It was injected with cortisone, without x-ray, and when she failed to improve she was referred to us with her diagnosis confirmed as osteogenic sarcoma. She refused surgery and chemotherapy and now has pulmonary metastasis. According to her mother who is an R.N., this girl, as a child, would lock herself in the family car when she needed DPT shots. She married her present husband after leaving her first, who went AWOL from the military service to try to patch up the faltering first marriage. Her present husband is currently on drugs and jobless. One certainly must realize that a patient's response to illness may be an additional burden to an already stressful life situation; special support is needed even when medical therapy is rejected.

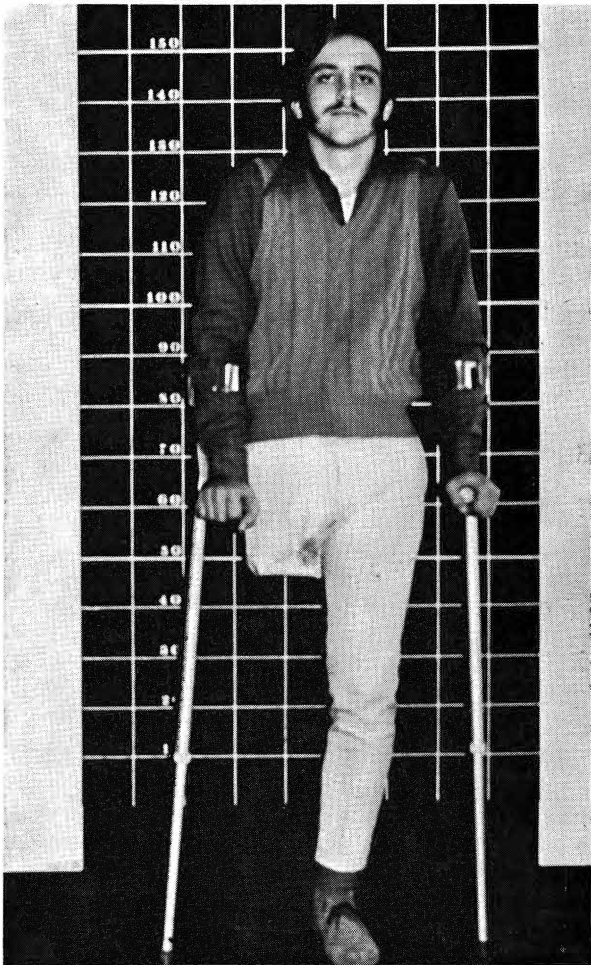


Fig 1—Amputation for osteogenic sarcoma.



Fig 2—Alopecia, the most common cause for altered physical appearance. A 7th cranial nerve palsy is also noted.

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Loss of a limb is a traumatic experience. It requires major surgery, and is followed by mourning of the limb and weeks of hard work on behalf of the patient and staff in the rehabilitation phase. Even then, the threat of a recurrence is always present.

At the Denver Children's Hospital we are fortunate to have an Amputee Center that aids in emotional support, early ambulation, prosthetic fitting and physical and occupational therapy. The youngsters are active in golf, riding, swimming and skiing. We have instituted a "buddy system" in which a well adjusted amputee visits, preoperatively, another teenager who must undergo amputation. We have recorded several of these sessions, with parents' consent, but unknown to the teenagers. Questions arise which we physicians are never asked, yet they are important to these youngsters: "Can I wear sandals?" "How do they take your leg off?" "What happens to my leg, do they bury it?" "When can I ski?" Perhaps we will gain more insight as we continue our project.

Endocrine changes secondary to surgery or radiation to the gonads may provoke castration anxieties. The cushingoid appearance with obesity and acne are especially unpleasant for these youngsters; low salt diets, good hygiene and hormonal replacement are helpful (Fig. 5).

Interpersonal Relationships

Ambivalence with respect to dependency-independency is intensified in adolescents with cancer. They may interpret as weakness the dependent role which the disease forces upon them and may resent their parents and physicians for making them appear weak. The frankness of their peers is difficult for the patients whose emotional reserve to respond to everyday trauma is already compromised by illness.

Normal heterosexual relationships may dissolve if the adolescent feels ugly and unworthy because of his illness.

Sympathetic or over-solicitous remarks may be infuriating; one girl changed colleges because she resented these attitudes. We point out to our patients that their friends may also be threatened by the idea of malignancy disfigurement and weakness; they may become self-conscious as does the patient and grope for the right way to react.

The attitude of the parents may be reflected in the adolescent's attitude toward his illness—the well adjusted parents who are eager to aid the physician in the total care versus the frightened or overprotective parents. Pre-existing distrust between the patient and parents or other authority figures may manifest itself in rebellion and resistance to staff and therapy. In general the adolescent must realize his physician is honest, interested, available and willing to spend time talking and listening. We should find out what is "bugging" these patients the most. Often other symp-



Fig 3—17-year-old girl with both hair loss and amputation. She made an excellent adjustment, with help from her family and boyfriend, and is shown with her wig, on the way to the Senior Prom.

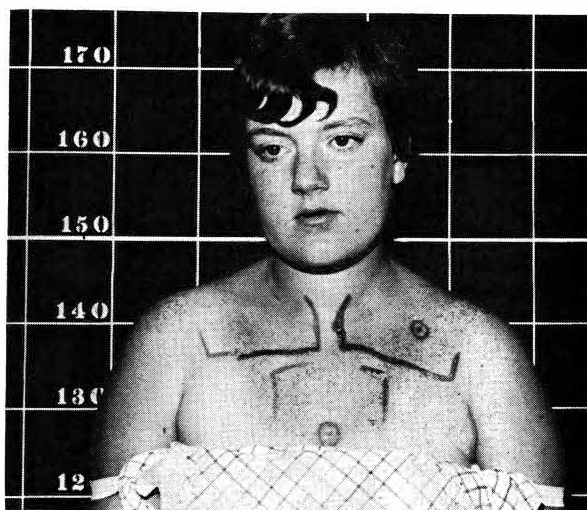


Fig 4—Skin changes in patient with Hodgkin's disease undergoing radiation therapy.

toms may make them feel a recurrence has come and they may be frightened and depressed.

Sibling rivalry may be evident if younger children are neglected by parents. Often their behavior may improve if the physician helps them understand why parents must occasionally devote more time to the sick sibling.

Often the doctor-patient relationship communications are non-verbal and are expressed in term papers patients write on leukemia, poems written when they are frightened or happy (Fig 6), and drawings they share with us. All have a message.

Future Plans

Questions asked often imply longevity: "Should I apply for college?" They really want to know: "Will I live long enough to finish college?" We are faced with the problem of giving an honest answer without demolishing hope for the future or encouraging false optimism.

The adolescent girl as she approaches adulthood witnesses her friends getting married and having children. She may wonder whether she should marry, have children, and what the effects of her past or present therapy would have on her children.

Pelvic irradiation, teratogenic anti-cancer chemotherapeutic agents, may seemingly make pregnancy impossible. Yet we have had girls conceive in and out of wedlock while on Vincristine, Cytosan® and 6-Mercaptopurine. Of course, problems of contraception or therapeutic abortion must be realistically discussed based on the girl's life situation.

The Management of Death

Adolescents may deny the prospect of death as a personal experience for themselves, even as they deny that they will ever grow old. Senescence and death are identified with weakness and imperfection. Any thoughts of death at the time of diagnosis will be smothered by the patient's denial and hope for a cure. During the course of the illness these patients commonly employ coping mechanisms such as denial, overcompensation, intellectualization and regression.

It is of interest that we have not seen any instances of drug abuse; rather there is usually a stoic rejection of pain medication unless it is obviously needed. There have been no overt suicide attempts within this group who are at the age where it is a common occurrence; life becomes precious.

Death is a very personal matter and yet the patient must feel his physicians will not abandon him—will not let him suffer pain or isolation. Many want to be at home in familiar surroundings, and members of the staff visit them at home. Many have asked that their bodies be donated to science and feel that in some way they have contributed through their ordeal of



Fig 5—Prednisone therapy causing cushinoid appearance in girl with leukemia.

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ALL TOO SOON

All too soon I will be grown up,
Never again to taste the pleasures
of childhood.
The days when rain was not something
to hide from;
The days when snow was not cold,
When snakes weren't slimey,
And Dogs did not smell,
When mud wasn't dirty and to play in.
These things are all past, long gone,
expired.
And I will never be innocent again.

Fig 6—Poem by adolescent patient with malignancy.

To Charlotte

Pain was what she knew.
Too young - but so old in pain.
It took the irony of malady
To bend her straight young back.
But mute, she obeyed the summons
To depart.
Like a hard young tree
Prints its shadow on the snows -
Or reluctantly lets go her leaves
On some sad, summer's day.
She, fading, fading
Will not go from our minds.
What we have seen and felt
(The tragedy of it!)
Etches its designs upon our brains
And we shall know.
Remembering her courage.
It was not in vain.

Helen Monroe
December 1969

Fig 7—By a mother, this poem shows that parents also need emotional support.



Fig 8—Drawing by a patient with Hodgkin's disease. Note the message on the flag; hope is important.

malignancy. Youngsters from broken homes even worry about funeral expenses for the surviving parents. The management of death is merely an extension of our management of life. It is the listening, reassuring and communication between people.

Parents and family must be comforted, guilt must be washed away, and they must be made to feel that everything possible has been done. Parents often visit or correspond with us years after a youngster has died, and must be supported even then (Fig 7).

Conclusion

A discussion on the psychological aspects in the management of adolescents with malignancy would be incomplete if we did not discuss the impact of this task as it relates to physicians and staff. Whether this is a once in a life time experience in a well general adolescent practice or a daily chore on a specialized oncology unit, it has profound emotional impact on all concerned. Those of us who see cancer patients as part of our daily routine develop our own coping mechanisms; they are variable and generally are the ones with which we are most comfortable. Whether it be a relaxed warm friendship or a more formal doctor-patient relationship depends on our own personalities.

Orientation for non-medical personnel, medical and nursing students, and housestaff is essential. Often these people have never faced adolescents with potentially fatal diseases and are often overwhelmed, frightened and depressed. They need a chance to ventilate these feelings and they need to know we have all felt the same way somewhere along the way, and do even now. They must also adapt the philosophy that a job must be done on a day at a time basis, with honesty, warmth, skill and kindness, because that is the way the kids want it. As illustrated by a Hodgkin's patient's drawing (Fig 8), "The show must go on."

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