REHABILITATION PROBLEMS OF FAMILIES WITH INDIVIDUALS SUFFERING FROM CANCER

USHA BHATT

Increasing survival rates for people suffering from chronic diseases like heart disease and cancer have led to an increase in the number and intensity of problems faced by families with long-term survivors from these diseases. Adapting to cancer diagnosis - responding, managing and restructuring is as much the task for the family as it is for the patient. Rehabilitation services are, therefore, needed not only by cancer patients but also by their families. Families face problems of conflicting demands due to the dual responsibility towards the patient and the family as a whole. The specific problems of families of cancer patients in India are due to illiteracy, superstition and lack of medical and employment facilities. 'Family rehabilitation' is a unique feature of two pilot rehabilitation research projects undertaken by the Indian Cancer Society in the last decade.

Dr. Usha Bhatt is Director, Rehabilitation Centre, Indian Cancer Society, Bombay 400 012.

Until the beginning of this century, the survival rates for people suffering from chronic diseases such as heart disease and cancer were very poor. The problems faced by their families were, therefore, short-term and few. During the last two or three decades, however, the survival rates from these diseases have increased dramatically due to improved methods of diagnosis and treatment and increased public awareness. For example, the survival rate for cancer has risen from one out of every six to three to four out of every six. As a result, the problems of families with long-term survivors from cancer have increased in number and have become more intense.

Cancer disrupts the lives of family members just as it does the patient's, and is a threat to the integrity and functioning of the family system. The diagnosis and treatment of the disease produce changes in the family's accustomed structure, patterns and roles - changes that call for a re-evaluation of old rules and a new flexibility (Anthony, 1978). Adapting to the cancer diagnosis - responding, managing, restructuring is as much the task for the family as it is for the patient (Levine and Scotch, 1970). Rehabilitation services are, therefore, needed not only by the cancer patients but also by their families. Except during theierminal stages, there has been little systematic documentation of the problems faced by families of cancer patients earlier. During the last two or three decades some studies have been undertaken by voluntary agencies for identifying the needs of families having cancer patients. In one such study, by the American Cancer Society (1979), 810 cancer patients and 142 families of surviving cancer patients were interviewed by trained and experienced social workers.

Nine priority problems were identified. These were (1) uncertainty about patient's health, (2) adverse effects on family household roles, (3) financial aid, (4) daily home help, (5) concurrent chronic illness, (6) loss of pre-illness life style, (7) inadequate supportive and referral services, (8) children's care and (9) sexual problems.

A major research goal in rehabilitation, is to prevent or reduce problems by interventions. Patients and families who have long term survivors from cancer, may not only experience persistent physical disability, but also suffer from psychosocial concerns, dilemmas and distress. It is, therefore, important to know if problems and concerns which arise early in the course of cancer, might be relieved by strategic and opportune

counselling or other kinds of intervention. Interventions include: resource provision, education, cognitive skills, training which includes behavioural techniques, crisis intervention, supportive interventions and insight oriented interventions.

Usual Family Reactions to Cancer

The very word "cancer" spells death and disaster to most people. The shock and strain of the diagnosis of cancer may either disorganise the entire family or key members may assert themselves and assist others to cope.

Panic: The immediate reactions of all concerned are understandably panic, bewilderment and anxiety. A common symptom is broken sleep patterns. Sedation may be required to ensure adequate rest. Another reaction may be an attempt to escape, sometimes through alcohol. Depression and crying spells, are not uncommon. The diagnosing physician may be the recipient of relatives' resentment, as if the diagnosis was somehow his or her fault. The goal of intervention is to overcome this despair and resentment by encouraging hope in all family members.

Helplessness: The family must deal with its feelings in tolerating the patient's suffering and anguish along with its own sense of powerlessness. The impact of cancer on both the patient and the family, as well as the ravages of the disease on the patient are perceived to be somewhat beyond the control of the family. Balancing helplessness with hopefulness is a difficult task for many families.

Accentuated ambivalence towards the patient is a concomitant of coping with long-term illness. Feelings of blame, guilt and shame may be engendered by the illness. Ambivalence may also be particularly strong when there is an expectation of lengthy illness or irreversible disabilities associated with long-term survival.

Uncertainty: Uncertainty is cancer's middle name, and families must cope with it. Even during periods of remission, families must delicately balance their hopefulness with the possibility of recurrence.

Needs of the family

Needs for Open Communication: Meeting the emotional needs of the patient by the family is very vital. Traditionally, the family has been considered the primary source of emotional support to those facing cancer. Facilitation of communication is the key to family support and counselling. In an American study, absence of open communication within the family was reported to be the second most frequent problem by the study group (Gordon, Feidenberg, Diller, Rothman, Wolf, Ruckdeschel, Hibbard, Ezrachi and Gerstman, (1979). Discussion of emotions between patients and family members is often difficult. Some have never developed the habit, and some are inhibited by the presence of cancer. One barrier is the natural need for families to protect the patients and others from the realities of cancer. Other communication barriers may occur later on, when the patients may conceal their true emotions to avoid upsetting family members, particularly those considered to be already overburdened. Family members may have vast discrepancies between their outward behaviour and their inner feelings. Like most people, they feel it is important to be cheerful and optimistic when dealing with a sick person. The facade may conceal quite different concerns. Physical change

in the patient from surgery or treatment-induced hair and weight loss, for instance, can give rise to varying degrees of aversion. Families may also be disconcerted by changes in the patient's behaviour, or by regression. Feelings of anger, sadness and depression over what is happening to the patient and concern for his or her future may be intense. These negative feelings, although they are directed at the situation, and not at the person, are difficult to express. Guilt about having such feelings may be another barrier to communication.

Meeting Needs of Children: In considering the effects of cancer on the family, the children of cancer patients should not be overlooked. Whatever their level of knowledge or ability to comprehend the meaning of cancer, children are aware that a tremendous change has occurred in the household. A study of the children in families with one well parent and one advanced cancer patient examined the impact of the illness on children of all ages (Chester and Yoak, 1984). At the time of the study, none of the parents had died, and many of the findings are transferable to a chronic illness situation. Some of the families exhibited extraordinary strength. Others with "average strengths and ability to parent" did not fare so well. Dealing with their own feelings and attending to the medical and financial aspects of the illness appeared to take priority over 'parenting'. The study found an extraordinary amount of regressive behaviour in young children (6 to 10 years old) who were kept unaware of the illness, compared with those who were told as much as they could understand. Children in the study exhibited a variety of cues interpreted as cry for help. Deteriorating school performance, physical and attention getting symptoms (sleep disturbance or bed wetting), eating disturbances, acting out or aggressive behaviour, refusal to obey, expression of hostility towards parents, depression and tears are some of the symptoms of emotional disturbances in children indicating the need for counselling. Cancer in a parent often creates an abrupt reversal of normal adolescent processes. Adolescent children were, therefore, found to have a great deal of behaviour problems.

Conflicting Demands: Families with long- term survivors from cancer have more than one life: one associated with the illness and its contingencies, and the other of being a family and experiencing the natural transitions as a family. This involves two super-imposed worlds, each with its own demands. Conflicts arise as part of the convergence of these two separate family lives. Families have a double duty. They must advocate for the index patient and their unique requirements, as well as advocate for the needs of the family members. Developmental tasks of the children go on including the members' needs for autonomy. The demands related to a long-term survivor may conflict with these needs.

Role Restructuring: With long-term survival, roles of family members are often realigned, reacquired and legitimated. The reassigning and acceptance of roles must also be by the other family members. Reorganisation is necessary to overcome the strain of multiple roles, and of new or additional tasks, while a family member is seriously ill. A sense of cooperation may ensure that family goals are met, and overcompensation by some members is relieved. Overcompensation by one member may lead to family conflict and competition. Equalizing tasks and consolidating resources can help promote family solidarity and shared responsibility for the care of the patient and the quality of family life.

Families can even learn and grow from the experience of cancer if they are willing to change patterns of relationships.

Aims of Family Therapy Programme

Not all cancer patients and families need to be taught communication skills. Some solve their own problems or adapt to the experience of cancer. Counselling and support by social workers can assist others. If family members indicate they are having difficulty, either by direct admission or by observed behaviour, referral to a family therapy programme (if available), is necessary. Health professionals, particularly nurses and social workers, are vital in providing support and helping families develop their own strengths. The basic aim of family therapy programme should include:

(1) Enhancing communication between the cancer patient, his or her family and friends.

(2) Enabling both the patient and family members to deal with their conflicts concerning serious or terminal illness.

(3) Working towards more direct and complete communication between patients, family members and physicians.

Family therapy, by addressing unresolved psychological and familial communication problems, can help all members to cope with the situation and can enable them to draw support from each other.

The first step when consulting with the family is a series of assessments. Developmental level-that is, the stage of the life cycle to which the family belongs-must be ascertained. Families with young children have vastly deferent needs from those with adolescent or grown up children. Secondly, the family's previous patterns in times of stress must be explored. If these patterns are not appropriate to the stress of cancer, family members may be assisted in finding new methods of adaptation. Family members should be encouraged in strengthening existing defenses and developing new strategies in living with the disease.

One hurdle facing family members is isolation, as family members are separated from one another in the fulfillment of disease-related tasks. Intervention should foster cohesion by defining needs and priorities and by helping the family locate material and social assistance. Facilitating communication can also foster cohesion. Over 70 per cent parents of children suffering from cancer who were interviewed in a study (Indian Cancer Society, 1977) reported that their spouse had been very or quite helpful. Social workers can help the family to learn about the disease by referral to booklets, brochures and other materials or by taking to them. Dealing with the emotional responses of others and rejecting unwanted advice is essential. Intervention that helps family members sort out their feelings, can provide the required courage they need to cope with outside influences.

Rehabilitation Problems of Families of Cancer Patients in India

In India it is estimated that every five lakh new cases of cancer are being diagnosed and that at any given time, there would be approximately 15 lakh people suffering from the disease. In future, this number is bound to increase with the increasing life expectancy of the Indian population. Compared to the vast number of cancer patients in India, facilities for their treatment and rehabilitation are very limited. Specialised treatment facilities for cancer are yet meagre in the country. At present, there are about

a dozen specialised treatment centres for cancer in the country, and only one rehabilitation centre for them. Reactions to cancer are universal. There are, however, differences in individual responses due to differences in cultural values. The degree of pain tolerance of the rural population in India is rather high because of the multiple problems they have to face in life. Poverty, illiteracy, age-old customs and superstitions, lack of proper medical and employment facilities and other basic amenities of life have aggravated the situation.

Family is still the basic unit of Indian society and family ties in India are stronger than in the developed countries. Although the basic principles of rehabilitation are the same everywhere, rehabilitation techniques and methods in a developing country like India must, therefore, take into consideration the family in any programme of rehabilitation. Assessment of needs of families of cancer patients and family rehabilitation *i.e.* teaching family members to cope with cancer and its consequences, was a unique feature of two pilot research projects on 'Rehabilitation of Cancer Patients and Their Families in Urban and Rural Areas' undertaken by the Indian Cancer Society during the last decade.

The Emotional Problems of Patients and Family Members

Unlike the West, where 50 per cent of cancer patients and their families were found to have major psychological problems, in Indian studies, cancer patients and their families were found to accept the disease and its consequences more easily because of the belief in the theory of *karma.* They therefore, were found to have less severe psychological problems. Their emotional problems were mainly related to adjustment to their changed circumstances. Instead of passive acceptance of cancer and its consequences, the rehabilitation personnel channelised this belief for constructive purposes of rehabilitation. Twenty-six emotional problems were identified for patients and 20 for the dependents. These are enumerated in Tables 1 and 2.

Table 1

FREQUENCY OF EMOTIONAL PROBLEMS OF PATIENTS BEFORE AND AFTER REHABILITATION AND THEIR PERCENTAGE REDUCTIONS

Emotional Problems of Patients	*Frequency at* T_1 *stages*	T_4	*Percentage reduction from* T_1 *to* T_4 *stages*
Tension due to physical discomfort	188	54	71.27
Tension due to side-effect of treatment	185	22	88.10
Tension causing frequent sleepless nights	198	188	5.05
Tension due to dependency in activities of daily living	177	40	77.40
Justification of illness as an outcome of past misdeeds (belief in *karma*)	191	181	5.23
Tension due to inability to continue treatment	53	19	64.15
Tension due to changed role in the family	169	18	89.34
Tension due to changed behaviour of the spouse	41	12	70.73
Worry about family	186	176	5.37
Desire to run away from family	49	1	97.95
Guilt due to inability to shoulder family responsibility	179	65	63.68

Feelings of burden on family	185	9	95.13
Fear of non-acceptance by relatives	157	46	70.70
Fear of non-acceptance by society	169	73	56.80
Lack of concentration on work	155	8	94.83
Lack of initiative	131	30	77.09
Frequent bouts of depression	194	111	42.78
Non-acceptance of changed body-image	187	38	79.68
'Why me' attitude	183	130	28.96
Worry about future	199	191	4.02
Irritability	92	6	93.47
Inferiority complex	150	24	84.00
Frequent thoughts of suicide	91	1	98.90
Unhappiness about sexual life	63	40	36.50
Frustration	198	190	4.04
Fear of death	195	191	2.05
Total	3865	1864	51.77

T1 - Before rehabilitation
T4 -1 year after provision of rehabilitation services

More than two-thirds of the emotional problems of patients were mainly related to health, and were reduced considerably after treatment. The remaining one-third of the problems were related to family, social and vocational areas and, therefore, reduced with counselling of patients as well as their family members and gaining of economic independence under the project programme. In case of the dependents, more than 50 per cent of emotional problems were substantially reduced, due to counselling and intensive casework. It was found that dependents faced more emotional problems than patients, because of their dual responsibility. As many as 80 per cent of the dependents had not been exposed to the outside world as they were students or housewives before the onset of cancer in the family. They, therefore, found it difficult to accept the changed circumstances.

Table 2

FREQUENCY OF EMOTIONAL PROBLEMS OF DEPENDENTS BEFORE AND AFTER REHABILITATION AND THEIR PERCENTAGE REDUCTION

Emotional Problems of Dependents	*Frequency at T1 stages*	*T4*	*Percentage reduction from T1 to T4 stages*
Dissatisfaction with own health	93	52	44.08
Fed up of illness in the family	187	56	70.05
Tired of taking family responsibilities	149	38	74.49

Upset over disturbed family routine	194	72	62.88
Fear of non-acceptance by relatives	18	2	88.88
Feelings of shame for being forced to ask for monetary help	181	115	36.46
Disturbed about strained relationship with relatives	188	123	34.57
Lack of concentration	104	4	97.14
Lack of confidence in acquiring new skills	83	42	49.39
Difficulty in getting a suitable job	174	95	45.40
Readiness to accept any work	74	19	74.32
Tension due to financial problems	197	177	10.15
Tension due to patient's illness	189	115	39.15
Desire to run away from family	49	2	95.91
Worry about future	199	188	5.52
Frequent thoughts of suicide	40	1	97.50
Unhappiness about sexual matters	108	50	53.70
Feelings of frustration	183	128	30.05
Frequent bouts of depression	197	48	75.63
'Why me' attitude	113	27	76.10
Total	2756	1354	50.87

* T1 - Before rehabilitation
* T4 -1 year provision of rehabilitation services

The lowering of the economic status brought about a corresponding lowering in the social status of the family as a whole, and of its individual members. Disability connected with cancer had serious repercussions on the socio-economic condition of the patient's family as a whole. Nearly 80 per cent of the patients in the study group were heads of families. The consequences were far more serious in case of large nuclear and joint families. The disablement caused by cancer also reduced the authority of the patient in the family, thereby creating many problems for the family which could only be solved with the help of the rehabilitation services provided under the projects. These are enumerated in Tables 3 and 4.

The solution of family problems was imperative for successful rehabilitation. The rehabilitation personnel found that once these problems were solved, the outcome of training improved. The problems of the families were solved through guidance, counselling and environmental manipulation and interventions. The social workers and the psychologist were the key personnel in both the projects who provided social and rehabilitation services to patients and their family members. These services included meeting their basic needs of food, clothing and accommodation, guidance regarding available services, counselling and intensive casework with patients and their family members, economic assistance for travel and emergency needs and referral to child welfare, family welfare and community services. The findings of both the research projects indicate that family problems were a definite barrier to successful rehabilitation

Table 3

FREQUENCY OF FAMILY PROBLEMS FACED BY PATIENTS BEFORE AND AFTER REHABILITATION AND THEIR PERCENTAGE REDUCTION

Family Problems of Patients	*Frequency between T1 stages*	*T4*	*Percentage reduction from T1 to T4 stages*
Food	193	19	90.15
Accommodation	191	9	95.25
Education of children	179	8	95.53
Care of children	150	56	62.66
Relationship with spouse	122	32	74.60
Relationship with other members	26	19	26.92
Treatment of family after onset of cancer	26	20	23.07
Clothing	179	8	95.53
Disintegration of family	32	19	40.62
Decision making in family	136	35	74.26
Change in family routine	173	39	77.45
Household work	188	30	84.04
Shouldering of responsibilities by other family members	151	32	78.80
Serving community meals	182	108	40.65
Performing festivals and weddings	187	78	58.28
Participation in community meals	171	32	81.28
Participation in ceremonies and weddings	169	26	84.61
Change in status of the family in community	176	96	45.45
Total	2478	669	73.00

T1 - Before rehabilitation
T4 -1 year after provision of rehabilitation services

of cancer patients. On the other hand, rehabilitation not only prevented family disintegration and dehabitation but also strengthened family integration.

Table 4

FREQUENCY OF FAMILY PROBLEMS FACED BY DEPENDENTS BEFORE AND AFTER REHABILITATION AND THEIR PERCENTAGE REDUCTION

Family Problems of Dependents	*Frequency between T1 stages*	*T4*	*Percentage reduction from T1 to T4 stages*
Food	178	1	99.43
Accommodation	165	4	97.57

Clothing	122	6	95.08
Education of children	121	45	62.80
Care of children	54	27	50.00
Relationship with spouse	15	4	73.33
Relationship with other members	8	4	50
Treatment by family	7	3	57.14
Disintegration of family	12	7	71.42
Decision making in family	36	13	63.00
Changed role in family	136	59	56.61
Change in family routine	165	68	58.78
Household work	86	46	46.51
Shouldering of family responsibilities	177	57	51.28
Change in status of the family	61	40	34.42
Total	1283	384	70.07

T1 - Before rehabilitation

T4 -1 year after provision of rehabilitation services

Conclusion

Families need people to draw and interpret their road map for them! Families of cancer patients need informative, interpretive and emotional support as they virtually experience the patient's illness. Since satisfactory psychosocial adjustment to cancer requires a strong supportive network, it may be more feasible to try to strengthen the patient's family, than to confront more directly the negative aspects of the patient's coping. A partnership model involving the doctor, the patient, his family and the social worker would be an ideal approach to rehabilitation in developing countries like India.

REFERENCES

American Cancer Society 1979 — Needs Assessment Study

American Cancer Society (INC) 1984 — *Proceedings of the Fourth National Conference on Human values and Cancer,* Professional Education Publication

Anthony, E.J. 1978 — The impact of mental and physical illness', *American Journal of Psychiatry,* 138-146.

Blumberg, B.; Flaherty M. and Lewis J. 1980 — *Coping with Cancer,* Maryland: Office of Cancer Communications, National Cancer Institute.

Chester, M. and Yoak, M. 1984 — 'Self-help Groups for Parents of Children With Cancer', *Helping Patients and their Families Cope with Medical Problems,* H. Roback (Ed) New York: Jossey-Bass.

Gordon, W.; Feidenberg, I. Diller, L. Rothman, L. Wolf C, Ruckdeschel, M. Hibbard, EzrachiO., and Gerstman, I. 1979 — The psychological problems of cancer patients, A retrospective study, presented at the American Psychological Association Meeting, San Francisco.

Indian Cancer Society 1977 — *Rehabilitation of Cancer Patients and their Families in Urban Areas, Bombay.*

Indian Cancer Society 1987 — *Rehabilitation of Cancer Patients and their Families in Rural Areas,* Bombay.

Levine S. and Scotch N.A. — *The Family as a Source of Stress, Social Stress.* Chicago: Aiding Pub. Co.