

PSYCHOSOCIAL STUDY OF LEUKEMIC CHILDREN AND THEIR PARENTS

G. Prasad Rao
Savita Malhotra
R.K. Marwaha

ABSTRACT

Psychosocial assessment was carried out in 35 children with acute lymphatic leukemia, an equal number with non-leukemic chronic illness and their parents. Psychological dysfunction existed more frequently in parents of leukemic children. Depression as an initial reaction on being conveyed the diagnosis, was seen in 85.8% whilst anger was observed in 42.8%. Majority (89.7%) entertained doubts about whether a correct diagnosis has been established. Understanding of the disease, its possible course and the need for prolonged treatment, was appreciated by about 65.7% of parents. The disease imposed serious social, financial and occupational burdens on the family. Measures used to cope with such stresses included meeting close friends and relatives and finding solace in religious activities.

When comparing psychopathology in leukemic children with that in chronically ill non-leukemic counterparts, significant differences were observed in certain specific syndrome scores. Conduct disorder, anxiety, depression and psychotic symptoms were more prevalent in leukemic children. This study emphasizes the necessity of active psychosocial intervention in the total care of childhood leukemia.

Key words: Psychosocial adjustment, Leukemia, Social burden.

Any terminal illness creates a heavy impact upon the concerned family members. The consequences of childhood cancer are much more severe in disturbing the mental health of the parents of these children(2,3). With modern advances in combination chemotherapy and supportive care in childhood leukemias, survival rates have considerably improved and therefore, there is a change of emphasis from one of preparing for death to one of preparing for life(4,5). Patients and parents have, therefore, to deal not only with the disease but also with the prolonged aggressive therapy which could be as distressing as the disease itself.

This study was aimed to assess the psychosocial difficulties and coping mechanisms in the parents of children with acute lymphatic leukemia (ALL) and to evaluate psychopathology in these children.

Material and Methods

Thirty five children with ALL and their parents attending the Pediatric Hematology clinic of this Institute were the subjects of this study. These children had been hospitalized in the pediatric ward for diagnosis, induction of remission, intensification and CNS prophylaxis according to a standard treatment protocol. Thereafter, they were on maintenance follow-up regularly at 4-6 weeks intervals. Apart from a detailed clinical assessment and hemogram at each visit, a bone marrow examination was done

From the Departments of Psychiatry and Pediatrics, Postgraduate Institute of Medical Education and Research, Chandigarh 160 012.

Reprint requests: Dr. Savita Malhotra, Additional Professor, Department of Psychiatry, PGIMER, Chandigarh 160 012.

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and pulse therapy with vincristine and prednisolone given every 3 months.

Before initiating therapy, the pediatrics consultant explained to the parents the nature of the disease, its likely implications and the prognosis. The necessity of prolonged treatment, strict compliance and regular follow-up was emphasized.

The control group comprised of 35, age and sex-matched children, suffering from non-leukemic chronic illness, such as nephrotic syndrome, diabetes mellitus and bronchial asthma, for a period of at least 6 months.

After obtaining informed consent the following assessment was carried out: (i) The Hamilton Depression Rating Scale(6) and PGI Health Questionnaire N2(7) were administered to each parent separately in both the groups, measuring neuroticism; (ii) A semistructured, pre-tested interview schedule was especially constructed for the purpose of this study to explore into the initial reaction of parents (anxiety, depression, anger, fear, doubt) and their attitudes towards illness, social burden and coping mechanisms. The interview was done first individually and subsequently with both parents jointly; (iii) The Childhood Psychopathology Measurement Schedule (CPMS) developed and standardized by Malhotra *et al.*(8) was administered exploring into the emotional/behavioral problem of children. This contained 75 questions which can be rated as being present (Score 1) or absent (Score 0). The total score was measured and scores of 8 factorially derived syndromes (low intelligence with behavioral problems, conduct disorder, anxiety, depression, psychotic symptoms, special symptoms, physical illness with behavioral problems and somatization) were determined.

Scores on Hamilton's Depression Rat-

ing Scale, PGI Health Questionnaire, and Childhood Psychopathology Measurement Schedule were compared in the two groups using 't' test.

Results

There were 31 (88.6%) boys and 4 (11.4%) girls in either group. The groups were also comparable in distribution of urban (65.7 and 60.0%) and rural (34.3 and 40.0%) living; and nuclear (50.0 and 62.9%) and joint (40.0 and 37.1%) family types.

Duration between initial diagnosis of leukemia and first psychological assessment was 6-12 months in 11 children, 13-18 months in 15 and more than 18 months in 9 children.

Comparison of scores on Hamilton's Depression Rating Scale in the two groups showed higher score for fathers (19.66 ± 3.45 and 17.81 ± 3.41 ; 't' value 2.73, $p < 0.05$) as well as mothers (28.97 ± 4.00 and 18.98 ± 3.41 ; 't' value 11.48, $p < 0.001$) of leukemic children than those of non-leukemics.

Similarly, neuroticism scores on PGI Health Questionnaire N2 were significantly higher in fathers (20.2 ± 2.62 and 16.42 ± 2.44 , 't' value 6.10, $p < 0.05$) and mothers (24.52 ± 3.16 and 19.61 ± 2.31 , 't' value 8.46, $p < 0.01$) of leukemic children in contrast to those of control group.

Initial reactions of the parents of leukemic children, when the diagnosis was conveyed to them, are depicted in *Table I*. All the parents showed depression which was moderate to severe in degree in 85.8%. Anger was present in only 42.8% of cases. General hostility was not a common feature, being present in only 5.6% of parents. A significant proportion (85.7%) entertained doubts about the diagnosis initially and the same number had a fear that the

TABLE I—Initial Reactions of Parents with Leukemic Children (n = 70)

	Absent		Present	
	No.	(%)	N	(%)
Depression	0	(0)	60	(85.8)
Anger towards doctor	40	(57.2)	0	(0)
General hostility	66	(94.4)	2	(2.8)
Doubt about the diagnosis	10	(14.3)	16	(22.9)
Fear of death	10	(14.3)	16	(22.9)
Death avoidable with proper treatment	9	(12.9)	1	(1.4)

child may die. However, majority (87.1%) also felt that the child may improve with proper treatment.

Twenty two mothers (62.9%) and 26 fathers (74.3%) from the leukemic group appreciated the illness to be a medical disease. The requirement for prolonged treatment was clearly understood by 23 mothers (65.7%) and 25 fathers (71.4%). However, almost all the parents (34 mothers and 34 fathers) believed that the illness may be due to ill fate or sins of previous life and felt that God could help them. In contrast, the majority, *i.e.*, 94.3% (33 fathers and 33 mothers) also felt that treatment would help.

Analysis of the burden faced by the parents revealed that approximately 83 to 97% of parents felt the burden due to the illness. Mothers of leukemic children felt greater severity of social burden (68.6%) than fathers (40.9%). In all other areas, *i.e.*, financial, family and occupation the presence and severity of burden were comparable in both parents of the study group.

The coping strategies employed by parents to overcome the psychological distress showed that the most significant and commonly used coping methods were spending more time with the patient (71.4% mothers and 57.1% fathers), seeking help from friends and relatives (68.6%

mothers and 65.7% fathers) and spending more time with family members (60.6% mothers and 45.7% fathers).

Table II shows the mean psychopathology scores in the children with leukemia in comparison with those of non-leukemic, chronically ill children. Though there were no significant differences between the total scores obtained in the two groups, significant differences existed in certain specific syndromes. Leukemic children had higher scores on the syndromes of conduct disorder, anxiety, depression and psychotic symptoms indicating more severe nature of symptoms; whereas the control group of children had significantly higher scores on the syndromes of special symptoms, physical illness with behavioral problems and somatization which depicts relatively non-specific and milder form of disturbance.

Discussion

The knowledge of any chronic illness in a patient provokes anxiety but the knowledge of a seemingly fatal illness like leukemia in their loved ones definitely distresses the parents more. In this study, none of the children had any acute symptoms at the time of evaluation. But still the parents exhibited depression and neuroticism. This probably reflects on the nature of disease. With the advent of intensive therapeutic

TABLE II—*Psychopathology in Children*

	Leukemic children (n = 35)		Non-Leukemic children (n = 35)		“t”
	Mean	SD	Mean	SD	
1. Low intelligence with behavioral problems	2.20	0.92	2.02	0.05	1.15
2. Conduct disease	4.51	1.20	3.28	1.16	4.34*
3. Anxiety	3.71	1.16	1.51	0.73	9.45*
4. Depression	4.68	0.97	3.28	1.16	5.38*
5. Psychotic symptoms	1.08	0.23	0.51	0.49	6.20*
6. Special symptoms	0.06	0.23	0.40	0.64	2.95*
7. Psychical illness with behavior problem	1.37	0.73	3.77	1.04	10.90*
8. Somatization	2.02	0.90	2.97	0.65	5.05*

* $p < 0.01$.

regimes, the effects of the therapy at times become as painful as the symptoms of the disease(9,10) causing continuation of depression in parents.

Between parents of leukemic children, it was the mothers than fathers who had significantly higher scores for depression as well as neuroticism. Females are found to be more prone to depression and neuroticism in a general population(7). Moreover closer emotional and psychological proximity of the mother to their children may be another factor to explain these higher scores in them. The parents of leukemic children as a whole appear to be more prone to develop psychological distress than those of the non-leukemic, chronically ill children. This finding is in accordance with the results obtained elsewhere(2).

Majority of the parents expressed doubts about the diagnosis which generally disappeared during the course of treatment. Most parents, however, had the fear that the child may die. Surprisingly, anger and hostility were not experienced by most parents.

A vast majority of parents blamed ill fate and sins of previous life to the cause of the illness which is in keeping with the prevalent socio-cultural belief in India. Many believed that God alone could help the child which can be construed as a defence that people normally resort to. On the other hand, most parents felt that medical treatment was the only answer to the illness of their children. This idea is not in contradiction with the preceding one. All it means is that parents felt that although medical treatment was essential but the ultimate outcome depended on God's will. This reflects the doctrine of 'Karma' (deeds of previous birth influence the present).

Social burden was present in the majority of leukemic parents and was more severe in the mothers. Moreover, constant needs of the patient in terms of time, care and finances, to meet the demands of expensive, prolonged treatment, may also have led to difficulties in other spheres causing burden. The mechanisms used by parents for coping with the burden of care

of a leukemic child were mainly religious and social and are the usual ones adopted in Indian culture.

In analyzing psychopathology of leukemic children in comparison with non-leukemic chronically ill control group, significant differences were observed in certain specific syndrome scores. The scores in the study group reflected more severe and specific psychopathology in them like anxiety, depression, psychotic disturbances and conduct problems. Although higher incidence of depressive symptoms is reported in children with cancer(12-14), these indicate psychological maladjustment rather than psychiatric disorder(15). In the control group these indicated general regression and non-specific emotional reactions which are common manifestations of distress in children with chronic physical illnesses(15-17). Pediatrics oncologists are, therefore, turning their attention to the psychosocial factors influencing the outcome of cancer treatment(9,18) and it is suggested that child psychiatrist should serve as a member of pediatric oncology treatment team(19).

This study has been carried out on the parents who had their children on active antileukemic therapy in contrast to many previous studies which have been done in parents who had lost their children due to malignant illness(2,17). It is essentially an initial exploration into the psychological dysfunction of leukemic children and their parents. It is apparent from the findings of this study that morbidity in leukemia is not merely related to the disease process and treatment. There is significant psychosocial morbidity in the patients and their families affecting their overall adjustment. Inclusion of psychological and social management in the comprehensive treatment plan

for such patients will certainly enhance the quality of survival of these patients.

REFERENCES

1. Spinetta JJ. Measurement of the family function: Communication and cultural effects. *Cancer* 1984, 53 (Suppl): 2330-2238.
2. Binglar CM, Feuerstein RC, Kushner JH, *et al.* Childhood leukemia emotional impacts on patient and family. *New Eng J Med* 1969, 280: 414-418.
3. Buzeman MF, Orbach CHE, Sutherland AM. Psychological impact of cancer and its treatment-III. The adaptation of mothers to the treatment and loss of their children through leukemia. *Cancer* 1965, 8: 1-19.
4. Lascari AD, Stephani JA. The reactions of families to childhood leukemia: An evaluation of a programme for emotional management. *Clin Pediatr* 1973, 12: 210-214.
5. Adams MA. Helping the parents of children with malignancy. *J Pediatr* 1973, 12: 210-214.
6. Hamilton MA. A rating scale for depression. *J Neurol Neursurg Psych* 1960, 23: 56-59.
7. Wig NN, Verma SK. Construction and standardization of PGI Health Questionnaire N2. *Agra Psychol Research Cell*, Agra 1979.
8. Malhotra S, Varma VK, Verma SK, Malhotra A. Childhood psychopathology measurement schedule: development and standardization. *Indian J Psychiat* 1988, 30: 325-332.
9. Meadows A, Hobbie W. The Medical Consequences of Cure. *Cancer* 1986, 58: 524-528.
10. Rowland J, Glidwell O, Sibley R, *et al.* Effects of different forms of central nerv-

- ous system prophylaxis on neuropsychological function in childhood leukemia. *J Clin Oncol* 1984, 2: 1327-1335.
11. Kocher G, O'Mulley J. *The Damocles Syndrome* New York, McGraw-Hill, 1981.
 12. Kashani J, Hakami N. Depression in children and adolescents with malignancy. *Can J Psychiatry* 1982, 27: 474-477.
 13. Rati DS, Jacobsen PB, Lederberg MS, *et al.* Characteristics of psychiatric consultations in a pediatric cancer centre. *Amer J Psychiatry* 1988, 145: 363-364.
 14. Glazer JP. Psychiatric aspects of cancer in childhood and adolescence. In: *Child and Adolescent Psychiatry—A Comprehensive Textbook*. Ed Melvin Lewis. Baltimore, Williams and Wilkins, 1991, pp 964-977.
 15. Spinetta JJ. Behavioral and psychological research in childhood cancer. *Psychol Bulletin* 1974, 81: 256-260.
 16. Malhotra S, Malhotra A. Psychological adjustment of physically sick children: Relationship with temperament. *Indian Pediatr* 1989, 27: 577-584.
 17. Pless IB, Roghman KJ. Chronic illness and its consequences: observations based on three epidemiological surveys. *J Pediatr* 1971, 79: 351-359.
 18. Mulhern RK, Horowitz ME, Ochs J, *et al.* Assessment of quality of life in pediatric patients with cancer: Psychological assessment. *J Consult Clin Psychol* 1989, 1, 1430-134.
 19. Pfefferbaum B. Common psychiatric disorders in childhood cancer and their management. In: *Handbook of Psycho-oncology: Psychological care of the patient with cancer*. Eds Holland JC, Rowland JH. New York, Oxford University Press, 1989, pp 544-561.

NOTES AND NEWS

UPDATE IN PEDIATRIC GASTROENTEROLOGY

An Update in Pediatric Gastroenterology in collaboration with some visiting Gastroenterologists from USA, including Professor E. Lebenthal, is scheduled to be held at New Delhi from 5th to 7th February, 1993.

For further details, please contact:

Dr. S.K. Mittal,
 Professor,
 Department of Pediatrics,
 Maulana Azad Medical College,
 New Delhi 110 002.