

## BURDEN OF CARE IN PARENTS OF CHILDREN SUFFERING FROM HAEMATOLOGICAL MALIGNANCIES

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### ABSTRACT

*The burden of care experienced by the parents of children suffering from haematological malignancies was the focus of the present investigation. Two groups of children—one with acute lymphoblastic leukaemia (N=23) and the other with hodgkin's disease (N=14) comprised the study sample. The key relatives of these children who also were the caregivers were assessed on a schedule of stressful life events, locus of control, burden of care, and neuroticism. In both groups, the number of stressful life events reported as well as the burden experienced by the relatives were comparable. It was observed that parents had anxiety even though the children were in a state of remission. The importance of recognising the burden experienced in the total management of child with a haematological malignancy is discussed.*

*Key Words : Burden of care, haematological malignancies, childhood leukaemia*

Practice of medicine and surgery now a days is heavily high-tech, perhaps highly commercial and to a certain extent dehumanising. Patients are treated but treating physicians and surgeons often give little thought to patient's and his/her relative's life circumstances, social network, belief system, quality of life or the cost of care and consequent burden of being ill and of being treated. It has been shown that life stresses, social support and networks, locus of control and burden of care are important and influential psychosocial variables affecting pathways to care, treatment compliance and outcome.

Any illness and more so, a chronic debilitating or a life threatening disease, poses or causes numerous psychosocial difficulties for those who look after such patients i.e. the caregivers. Such difficulties undergone or faced by the caregivers are collectively subsumed under the title of burden of care. The concept of social burden of care is from the realm of

behavioural sciences primarily in the context of looking after a psychiatrically ill person where the underlying frame of reference is those problems 'related to'; 'due to' or "caused" by the patient's illness. The concept of burden is linked to social performance as well in as much that one person's poor social performance (i.e. the patient) is another person's burden (e.g. the caregivers). Two types of burden have been described—objective burden which included anything that occurred as a disrupting factor in family life owing to patient's illness, and subjective burden which referred to the feeling that a burden is being carried in subjective sense (Hoening & Hamilton, 1996).

There is no universally accepted definition of burden of care. Trendley (1946) first used the term burden on the family in relation to the consequences for those in close contact with a psychiatric patient. Platt (1985) proposed that "social burden or burden of care refers to the presence of problems, difficulties or adverse

events which affect the life (lives) of a psychiatric patient's significant others, e.g., members of the household and/or the family". Goldberg & Huxley (1980) defined social burden as the "effect of the patient upon the family". Brown (1967) considered it as the impact of living with a patient on the way of life and health of family members".

What is true for psychiatric illness is also applicable to physical illness as majority of our physically ill persons are treated at their homes. In physical illnesses, the existence of burden indicates the breakdown of reciprocal arrangements that people maintain in their relationship. Thus, because of physical illness in the family, one member of the family ends up doing more than his fair share of the work of looking after the patient. This may result in one member in the family taking on a greater proportion of shared tasks but this may also lead to restriction of activities outside this familial relationship. This change in pattern, when assessed against how family members are expected to perform social roles, gives a fair idea of objective burden. Not only this, such change in the pattern of task performance also leads to and is accompanied by a subjective sense of dissatisfaction.

The presence of a sick child in the family is distressing at any time and this distress is more acutely felt if the child happens to have a serious disorder with reduced life expectancy such as malignancy. Advances in paediatric oncology has increased considerably the rate of survival in childhood malignancies. Progress in cancer therapy has transformed the psychological dilemma from one of adapting to the possibility of death to one of coping with uncertain survival (Eisenberg, 1981).

The initial parental responses to the diagnosis can be characterised as a state of shock that may last for several weeks (Koch et al., 1974; Lansky, 1974; Lansky et al., 1978). Severe neurotic symptoms often appear during this phase. Anxiety and depression may occur in nearly 50% of the parents although most of these subside or disappear spontane-

ously during the treatment (Magurie et al., 1979). After recovering from the initial shock, most parents are able to take care of their child and adequately fulfil their responsibilities (Koch et al., 1974; Pearse, 1977; Kupst & Schulma, 1980) so much so that one year after the initial diagnosis parents have been reported to be coping well (Marky, 1982). Although there is reduction in the levels of anxiety and depression from the stage of initial diagnosis, yet these continue to be high in many cases and persist even after the termination of therapy of the child (Magni et al., 1983; Koocher, 1984).

Many workers have noted that the stress of coping with a child who had leukaemia caused health problems, alcohol abuse, social withdrawal, sexual and marital difficulties and problems at work (Maguire, 1980; Morrow et al., 1981). It is also reported that childhood leukaemia aggravates already existing interpersonal problems (Maguire et al., 1979; Peck, 1979). Lansky et al (1978) reported that the quality of marital relationship in parents with a leukaemic child suffers and such parents tend to have more disharmony though there is no evidence of actual increase in divorce in these couples.

For the parents of these children, treatment involves emotional as well as physical burden in addition to the threat of loss. Such parents must accept the complexities of treatment without any guarantee that it will cure the disease (Levine & Hersh, 1982). Parents have to deal with the procedures of informed consent (Johnson et al., 1979), the suffering of their child, hospitalisation and repeated visits to the clinic (Maguire, 1983), considerable financial expenses (Lansky et al., 1983) and the disruption of family routine (Levine & Hersh, 1982; Ross & Klar, 1982). The presence of a leukaemic child in the family means that the each member of the family must adapt to the changing family rules and roles. The illness also requires a re-orientation of family values, goals and expectation.

Paediatric oncology in our country is now gaining in stature and an increasing number of

children with various malignant disorders are seen by paediatrician and allied specialists. However, psychological impact of such a child on the parents and family have not been investigated in our country. Also, the data about the burden of care of such children in our setting are woefully lacking. Because of these reasons the present work was undertaken.

The investigation was carried out with the following aims :

1. To assess the burden of care of a child with haematological malignancy experience by the parent.
2. To explore the relationship between clinical and psychological variables and the burden reported.

### MATERIAL AND METHOD

The study was carried out in the haematology clinic of the department of paediatrics, PGIMER, Chandigarh. The diagnosis of a haematological malignancy was arrived at by one of us (RM) using current research criteria for the diagnosis of acute lymphoblastic leukaemia-ALL and hodgkin's disease-HD. These were consecutive cases. Utilising the assessment instrument as described below, the key informants of these child were evaluated by one of us (KD). These assessment were cross - sectional and done once only.

The following assessment instrument with documented inter-rater reliability and face validity were used :

1. Family burden interview schedule of Pai and Kapur (1981) : The scale has 24 items. The subject is interviewed in a semi-structured manner. The areas of burden covered by the scale are -i) financial, ii) family routine, iii) family interaction, iv) family leisure, v) physical health and iv) psychological health. These are measures of objective burden. Subjective burden is measured by a single question. Each item is rated on 3 point scale-a score of 0 denoting no burden and a score of 2 denoting severe burden.

2. Presumptive stressful life events scale of Singh et al (1984) : This is a schedule which was standardised on Indian population and has 51 items assessing various life event experienced by the subject. The method of administration is a semi-structured interview and the time frame for assessing the occurrence of a life event (s) is the year preceding the interview. The event are listed in a hierarchical manner-the most traumatic being death of spouse to the least being going on a pleasure trip/pilgrimage. The events are divided in three categories - desirable, undesirable and ambiguous. Another way of dividing the events is on the basis of nature of the event i.e. whether the event is dependent or independent. The scoring of events is done in two ways: i) number of events, and ii) stress score. This can be done for all events, type of the event or for the nature of the event.

3. PGI N<sub>2</sub> health questionnaire of Verma (1978): This questionnaire was developed in our own department of psychiatry and is a measure of neuroticism which is defined as a propensity to develop neurosis under stress. The questionnaire consists of 60 items - 50 items measuring neuroticism and 10 measuring lie score i.e. tendency to give socially desirable responses. This scale has been used quite widely in psychiatric research and has proven psychometric properties. Scores of 9 and above indicate neuroticism and a score of 4 or above on the lie scale helps to reduce false negatives.

4. PGI locus of control scale of Menon et al (1988) : This scale was also developed in our department as the western scales were found to be too complicated for use in Indian population. This scale is quick, simple, objective and reliable. This scale is in Hindi and consists of 7 items. Each item has 3 choices. The scoring is done on a 3 point scale. Maximum score that can be obtained is 14 and higher the score greater is internal control. Lower score denotes external locus of control.

Before taking the parents for the study,

they were briefed about the nature and purpose of the investigation and their informed consent was obtained.

## RESULTS

Thirty seven children with haematological malignancies -23 acute lymphoblastic leukaemia(ALL) and 14 with hodgkin's disease (HD) formed the sample of the study. The mean age of children in ALL was 9.52 (SD 3.49) years and that of HD children was 7.93 (SD 3.05) years. There was no statistically significant difference between the 2 groups. Similarly, there was no statistically significant difference in age between the parent of ALL and HD children (mean age 37.48 (SD 9.25) years and 34.36 (SD 7.42) years respectively).

At the time of psychological evaluation, nearly 65% of ALL cases and 43% of HD cases had been ill for more than 2 years. With regard to the status of the disease, nearly 69% of ALL cases and 78% of HD cases were either in remission or their disease was in control. The rest were either uncontrolled or had relapsed. The families these children seemed to have spent a great deal of money on treatment. As reported by the parents, nearly 92% of them had spent between Rs. 25,000 to Rs. 50,000 and about 8% had spent more than Rs. 50,000 on the treatment of their sick youngster.

Stressful life events as experienced by the parents are shown in table 1. The two groups did not have any statistically significant differences with regard to either number of stressful events or stress score. When the propensity for neuroticism was assessed (PGI N<sub>2</sub> Health Questionnaire), it emerged that both groups had high scores on neuroticism but there was no statistically significant difference (table 1).

The two study groups of parents had almost similar locus of control. The mean score for ALL group was 10.43 (SD 3.22) and that for the HD group was 9.86 (SD 2.68). There were 12 "internals" and 11 "externals" in the ALL group and the corresponding figures for the HD groups were 9 and 5.

TABLE 1  
STRESSFUL LIFE EVENTS EXPERIENCED BY THE PARENTS AND NEUROTICISM SCORES

	ALL	HD	t value *
Number of events			
mean	4.65	5.07	0.52
SD	2.06	2.46	
Stress scores			
mean	209.87	226.93	0.47
SD	91.25	108.68	
Neuroticism			
mean	8.96	12.57	1.07
SD	10.07	9.037	
Lie			
mean	0.69	0.78	0.22
SD	1.22	1.12	

\*all values not significant

TABLE 2  
BURDEN OF CARE IN PARENTS

	ALL	HD	X <sup>2</sup>
Global			
none	2	1	
moderate	9	6	NS
severe	12	7	
Subjective			
none	2	1	
moderate	10	8	NS
severe	11	5	

TABLE 3  
BURDEN OF CARE IN PARENTS  
(expressed in percentages)

Burden	ALL		HD		X <sup>2</sup>
	present	absent	present	absent	
Financial	83	17	93	7	4.72*
Family routine	83	17	86	14	NS
Leisure	61	39	71	29	NS
Interaction	61	39	57	43	NS
Phy health	43	57	57	43	3.92*
Mental health	65	35	71	29	NS
Global	91	9	93	7	NS
subjective	91	9	93	7	NS

\* significant at p<0.05.

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TABLE 4  
RELATIONSHIP OF BURDEN WITH CLINICAL AND PSYCHOSOCIAL VARIABLES IN ALL GROUP

	Financial	Family routine	Family leisure	Family interact	Physical health	Mental health	Subjective	Global
Duration of illness	0.46	0.34	0.32	-	-	-	0.33	-
Hospitalisation	0.41	-	0.39	0.34	-	-	-	-
Number of life events	-	-	-	-	0.33	0.37	-	0.42
Stress score	-	-	-	-	0.32	0.38	-	0.43
Neuroticism	0.30	0.45	0.59	0.44	0.54	0.48	0.40	0.63
Locus of control	-	-	-	-	-0.49	-	-	-0.50

all r values are significant at  $p < 0.05$

The results of the assessment of burden of care in these parents are shown in tables 2 & 3. Only 3 parents, 2 in ALL group and 1 in HD did not admit that they had any burden either objective or subjective. The rest had moderate or severe burden. However, there was no statistically significant difference between the two groups (table 2). Examination of various areas of burden revealed that financial burden was the most common aspect of the experienced burden and the HD groups had significantly more burden than the ALL group. Disruption of family routine and family leisure activities were the two other most commonly affected areas. Looking after a child with leukaemia had caused significantly more physical health problems in the parents of HD group compared with ALL group (table 3).

The relationships between burden of care and various psychosocial and clinical variables are shown in tables 4 & 5.

In ALL group, financial burden had significant correlation with duration of illness, number of hospitalisation and neuroticism scores of the parents. Disruption of family routine had significant correlation with duration of illness and neuroticism scores. Family leisure activities had significant correlation with duration of illness, number of hospitalisation and neuroticism scores. Disruption of routine

family interaction had significant correlation with number of hospitalisation and neuroticism scores of the parents. Physical health of the parents was associated in a significant manner with number of life events, total stress score, neuroticism and the locus of control. Locus of control had negative correlation indicating that the illness had greater impact on the physical health of those who were "externals". As regards impact on the mental health of the parents in concerned, it had significant correlation with number of stressful life events, total stress score and neuroticism. Subjective burden had significant correlation with duration of illness and neuroticism (table 4). Thus, duration of illness and the propensity for neuroticism in the parent emerged as major contributors in determining the pattern of burden.

The relationship between various areas of burden and the psychosocial variables in HD groups was somewhat different than ALL group. In HD groups, the duration of illness does emerge as the major contributor towards burden. Neuroticism and life events appear to be major determinants of burden in this group. These results are shown in table 5.

## DISCUSSION

Burden of care is an important yet often

TABLE 6  
RELATIONSHIP OF BURDEN WITH CLINICAL AND PSYCHOSOCIAL VARIABLES IN HD GROUP

	Financial	Family routine	Family leisure	Family interact	Physical health	Mental health	Subjective	Global
Duration of illness		-0.37	-	-	-			-0.43
Stage of illness				0.38				
Cost				0.45				
Number of life events	0.55		0.48	0.45		0.42		
Stress score	0.62		0.55	0.54	0.39	0.45		0.60
Neuroticism	0.69	0.44	0.76	0.68		0.67		0.45
Locus of control		-0.37	-0.52			-0.40		-0.45

all *r* values are significant at  $p < 0.05$

neglected aspect of the management of patients with cancer. We have studied burden of care in parents of children with childhood haematological malignancies namely acute lymphoblastic leukaemia and hodgkin's disease. These two diagnostic groups were taken for the study because both these conditions are quite common in children. Moreover, it was felt that assessment of burden in these two conditions which have different course and prognosis would generate data, analyses of which might yield results highlighting the contrast of burden experienced. The study sample is small. Even then this investigation clearly shows that parents of children with haematological malignancies do perceive moderate to severe burden. It is also worth noting that parents experienced burden despite the fact that the majority of the children were either in remission or their disorder was under control. Both the groups of parents had high scores on neuroticism. It is quite likely that the stress of caring for a sick child as well as level of perceived burden have led to this.

On exploring various areas of burden it became apparent that financial and disruption of routine family activities were that two areas

in which the burden was chiefly felt. Also, majority of parents carried burden in a subjective sense. Significantly, a larger number of parents of HD children had financial burden as compared to parents of children with ALL. The illness of the child also had damaging effect in significantly greater number of parents of HD than parents of all children. These differences could partly be due to chronic course as well as longer duration of illness of hodgkins's disease.

Different stages of psychosocial adaption by the parents to the malignancies in their children have been described with each stage having its adaptive task to accomplish (Van Dongen-Melman and Saunders-Woudstra, 1986). In this context, the parents of this study sample belonged to different stages of psychological adjustment because of variable length of time the children had been ill. Thus, what has been assessed is the global burden of care collectively reflecting the summation of various stages of psychological adaptation.

Going by this study, there appears to be a need to explore these areas in caregivers and parents of children with malignant disorders. This is all the more important as attention to

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these aspects would enhance the quality of total care rendered to the patients had their caregivers. The necessity to evolve coping strategies to effectively deal with burden of care is self evident.

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