

ORIGINAL ARTICLE

**DEPRESSION AND ANXIETY IN MOTHERS OF  
CHILDREN WITH CANCER AND HOW THEY COPE  
WITH IT: A CROSS-SECTIONAL STUDY IN  
EASTERN INDIA**

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**Abstract**

**Objective:** Cancer is a chronic, long-term illness that affects not only the child but also the family as a whole. The family faces objective as well as subjective difficulties, e.g. stress, anxiety and depression. The burden is often experienced by mothers, since they take on the major responsibility of care giving. We conducted a study in mothers of children with acute lymphoblastic leukemia (ALL) and determined whether their coping mechanisms were acceptable and if these mechanisms were helpful to reduce depression. **Methods:** Mothers of 58 children with Pre (precursor) B cell leukemia were evaluated using Beck's depressive inventory (BDI), Coping Health Inventory for Parents (CHIP), and State-Trait Anxiety Inventory (STAI). **Results:** Coping with behaviors used by mothers of children with ALL was ineffective. The mothers mostly used coping behavior, which involved family life and relationships, and the parents' outlook on life of the affected child. The use of CHIP sub scale-type I, ie. "talking with other individuals/parents in my same situation" was significantly related to more use of sub scale-type II, ie. "doing things together as a family, involving all members of the family" are both were significantly related to STAI ( $p < 0.001$ ). However total BDI score was not significantly related with any of the coping scores (BDI scores more than 9). Patients with higher BDI scores had lower scores in all sub scales of CHIP. **Conclusions:** Our subjects did not use social support and did not understand the medical situation through communication with other parents, or medical professionals. Fewer depressed patients used more coping skills. Educating the parents about healthy coping mechanism can be a good way to reduce stress. Encouraging social support networking and providing information about the disease may help to increase the acceptance among the mothers with ALL. *ASEAN Journal of Psychiatry, Vol. 17 (1): January – June 2016: XX XX.*

**Keywords:** Depression, Anxiety, Mothers of Children with Cancer, Coping Mechanism, India

## **Introduction**

Parents describe the diagnosis and treatment of a child with cancer as one of the most stressful times in their lives [1]. The difficulties for families may be objective, such as financial needs, housekeeping, and work activities. Subjective difficulties refer to the emotional reactions that family member's experience, such as communicating with siblings of the ill child and concerns about the child's future and depression. Providing emotional and physical care for their child not only increases the mother's workload but may cause her own physical health to suffer. In a recent study, mothers reported higher level of stress than fathers. Various studies have shown that mothers display symptoms such as hopelessness, despair, anger, stress, anxiety, and depression [2].

Very handful Indian studies are available in this area. However, a study in Canada assessing cultural beliefs and coping strategies related in South Asian immigrant parents of children with cancer showed that parental coping strategies included gaining information about the child's cancer, practicing religious rituals and prayers, trusting the health care professionals, and obtaining mutual support from other parents [3]. Sharan et al studied the coping and adaptation of parents of children with ALL with TAT (Thematic apperception test-Indian adaptation). Emotional distress was evident in the stories of 83%, only 37% maintained an expectation of a positive outcome [4]. The life situations of these parents demand exceptional psychological resources. The interplay between demands and resources of parents whose child has cancer is often referred to as "coping", commonly defined as the cognitive or behavioral effort to eliminate the negative emotions elicited by excessive demands [5].

Among the vast groups of pediatric cancers Acute Lymphoblastic Leukemia (ALL) is the commonest type. ALL accounts for approximately 70% of childhood leukemia (0-19 years). It has a peak incidence at 2-5 years, decreasing in incidence with increasing age. ALL is slightly more common in male than female. Classification of ALL based on

immune-phenotype (done by cytogenetic test, flow cytometry and other lab test) are Early Pre-B cell (60-65 %), Pre-B Cell (20-25%), Mature B Cell (2-3 %) and T-Cell (15-18 %). This Classification has been useful in predicting clinical outcome as well as determining treatment options. ALL is treated by chemo therapy, steroid, radiation therapy; and intensive combined treatment (including bone marrow transplantation). Currently, the survival rate of ALL has improved due to new chemotherapeutic agents and Stem cell transplantation (SCT). In India each year, over 6000 children under 15-years age developed ALL [6].

Medical College and Hospital are a tertiary care center situated in the city of Kolkata, West Bengal, Eastern India. It gets about 30 new cases per month of ALL patients (pediatric), amounting to almost 350-400 patients each year. Most of the patients remain admitted during intensive phase of therapy (1<sup>st</sup> phase of the management), and their caregivers in 99% cases have been their mothers. So we wanted to explore the emotional reactions of the mothers and how well they are coping with this situation. We studied the cases where at least one month has passed after the diagnosis, and we questioned about their mental states and how they had been coping with this adverse situation. Our objective was to assess: (i) whether coping mechanisms used by the mothers were adequate; (ii) which coping mechanisms were helpful to reduce depression; and (iii) which of the coping mechanisms they had been using the most and which the least.

## **Methods**

### **Materials**

*Beck depressive inventory (BDI)*, Bengali version is a self-rated 21 item scale. This widely used instrument consists of 21 symptoms or attitudes commonly seen in patients suffering from depression (e.g. sadness, negative self-concept, sleep and appetite disturbances). The symptoms are rated from '0' to '3' in intensity. However, we should be cautious regarding use of the term depression from a single-administration BDI

because internal consistency for non-psychiatric subjects has yielded a mean coefficient  $\alpha$  of 0.81, and the mean correlation of BDI with clinical ratings on the Hamilton Psychiatric Rating Scale for Depression has been found to be 0.74 suggested and recommended that the term depression should only be used when individuals score above 20 on the BDI. The following cut-off points of depressive symptomatology are recommended. The range of scores from 0-9 indicates no depression, 10-20 dysphoria and  $> 20$  depressions. Depression scores above 9 are referred to as elevated depression scores. It's Bengali version has already been validated [7-9].

*Coping Health Inventory for Parents (CHIP)* is originally developed by MacCubbin et al in 1983 this scale assesses coping styles and perceptions of the helpfulness of certain strategies of parents of children with chronic illness. Initially used in parents of children with cystic fibrosis this scale uses a four-point Likert-type scale, ranging from 'not helpful' (0) to 'extremely helpful' (3). Forty-five items are divided into three sub-scales; family (maintaining family integration, co-operation and optimistic definition of the situation), support (maintaining social support, self-esteem and psychological stability), and medical (understanding the medical situation through communication with other parents and professionals). [10] For adaptation of the scale, CHIP questionnaire was translated from English into Bengali. An expert panel of three bilingual content experts verified the equivalence between the original and Bengali versions of the instruments. A language expert (a bilingual and PhD in linguistics) also participated in the verification process. Once consensus was reached among panel members in terms of equivalence between two versions, a nonprofessional bilingual individual was interviewed to assess the precision of the translated version. The translated instruments were then used for data collection. The validation process of CHIP in Bengali is going on. We have just now completed the pilot study.

*The State-Trait Anxiety Inventory (STAI)*. This inventory was designed by Spielberger, Gorsuch, Lushane, Vagg and Jacobs (1983)

not only for the assessment of the anxiety loading of the individual but also for the distinction of two aspects of anxiety viz. state anxiety and trait anxiety. State Anxiety is conceptualized as a transitory level of anxiety, which fluctuates with time and circumstances, whereas, Trait Anxiety is regarded as a latent predisposition, which is relatively stable and can be triggered by appropriate stimuli.

STAI is a self-evaluation questionnaire. Both part of the inventory contains 20 items each. Items of this scale have been constructed in reverse- and non-reverse-keyed format, and instructions are given asking participants to rate their agreement with a statement on 4-point "Likert-type scale". We took the Bengali version which is a validated one and being used extensively in Bengali [11].

## **Methods**

The study group included all the willing mothers of 58 children with pre B cell leukemia with ongoing treatment for cancer whose children were admitted in the hospital during the study period. After getting ethics committee clearance cases were selected from admitted patients from the department of pediatrics, Medical College & Hospital, Kolkata, and West Bengal, India. Mothers were accompanying the children. All mothers were informed about the diagnosis, treatment protocol and prognosis. They were also given a brief description about the nature and objective of the study. Only mothers having education above fifth standard were selected because the assessment scales were self-rated. For the same reason only Bengali speaking patients were selected. Socio demographic data were recorded. All 3 scales were given to the mothers.

Literature suggests three criteria to be used while assessing the adequacy of parental coping with chronic life-threatening illness in children: (a) the number of coping behaviors employed by parents [10, 12], (b) the comparison of parental scores with those of the "index of normative data" presented in Table 2 [12] and (c) the comparison of parental scores with those obtained in other similar studies, which have made use of the CHIP and have indicated effective coping.

According to our knowledge, the CHIP scale has not been used in any Indian studies so far.

So we used first two criteria only. Regarding criteria (a) coping strategies ‘Reading more about the medical problem which concerns me’, ‘Taking good care of all the medical equipment at home’, ‘Reading about how other persons in my situation handle things’ were reported as not used by most of our subjects. We tried to compare the chip scores with the “index of normative data “ of Maccubbin [12] keeping in consideration that the population undertaken in the study is different and the scale is not validated in our population.

Descriptive statistics were used to describe the most helpful coping strategies and to calculate the total score for each subscale of the CHIP. In case any strategy was reported as ‘do not use’/‘not useful’ participants were asked to explain the cause. Correlation was carried out

among BDI, state and trait anxiety score and scores of 3 subscales of CHIP scores.

Participants were divided into three groups depending on their BDI score (not depressed, dysphoric and depressed) and their scores were compared.

## Results

Age range of the children was 2 years – 12 year average being 5.7 years whereas that of the mothers was 28 years – 48 year and 29 year respectively. Average per capita income of the families was 865 rupees (equivalent to 12 US dollar) per month, and the mean educational exposure of mothers was 8.03yrs (SD - 3.08). About 60% of our patients were male and 40% were not going to school at the time of assessment. Duration of treatment was less than 6 months in case of 28 (46.7%) patients, 6-12 months in 22 (36.7%) and rest had more than 1 year duration (Table1). About 75% came from a rural background.

**Table 1. Sociodemographic profile of the patients**

	Mean	Range	Standard deviation
Age of children (years)	5.74	2-12	2.76
Age of mothers (years)	28.93	22-48	6.4
Per capita income/month (Rs)	865.52	200-3500	729.12
Education of caregivers(years)	8.03	3-14	3.08

To assess adequacy of our mothers coping, the sample’s scores were compared with the index of “normative” data provided in the literature

[12] and it shows that our study group used less coping strategies (Table 2).

**Table 2. Comparison of means, standard deviations (SD) and ranges (R) on the CHIP scale and its subscales of the present study population and that of McCubbin et al**

Scale & subscales	Current study, N=58			McCubbin et al. (1983), N=308		
	Mean	SD	Range	Mean	SD	Range
Family integration	26.28	3.8	16-33	40	15	25-55
Support, esteem, stability	20.55	6.5	7-32	28	12	16-40
Medical communication	11.66	1.9	7-15	15	8	8-22

Table 3 shows highest ten coping strategies perceived as being helpful by the mothers. Seven of the prime ten strategies were related to positive definition of the situation and strengthening family life (coping pattern, I).

Most helpful one was ‘Talking with other individuals/parents in my same situation’. All except two participants used it, and about 60% of them found it extremely helpful. Coping strategies ‘Reading more about the medical

problem which concerns me' (III), 'Taking good care of all the medical equipment at home' (III), 'Reading about how other persons in my situation handle things' (III) were reported as not helpful. The cause being the sample was taken from a government hospital, and it caters mostly people of lower socioeconomic condition (average per capita income of the families was 865 rupees per month and the mean educational exposure of

mothers was 8.03yrs). 'Reading' is not a preferred mode of passing leisure time or entertainment in this group. Moreover, very few had access to the information like internet, library etc. Most families had no medical equipment at home. 'Developing myself as a person' (II), 'Keeping myself in shape and well-groomed' (II), 'eating' (II) was also less helpful. Mothers reported that they were so anxious and depressed that they are not in a state of thinking about their looks.

**Table 3. Top ten most helpful coping strategies**

Coping pattern	Coping strategies
I	Talking with other individuals/parents in my same situation.
I	Doing things together as a family (involving all members of the family).
I	Believing that my children will get better
II	Trusting my spouse (or former spouse) to help support me and my children.
I	Talking with other parents in the same type of situation and learning about their experiences
III	Believing that the medical center/hospital has my family's best interest in mind
I	Doing things with my children
I	Believing that my child is getting the best medical care possible
I	Doing things with family relatives
II	Concentrating on hobbies (art, music, jogging, etc.).

Table 4 shows correlation between coping and maternal depression and anxiety. The use of coping pattern I was significantly related to more use of coping patterns II ( $p < .001$ ), both

were significantly related to stating and trait anxiety inventory. However total BDI score was not related with any of the coping scores.

**Table 4. Correlation between coping and maternal depression and anxiety**

Variable	BDI <sup>^</sup>	Coping pattern I	Coping pattern II	Coping pattern III	State anxiety score
BDI					
Coping pattern I	-.362				
Coping pattern II	-.279	.862**			
Coping pattern III	-.228	.104	.114		
State anxiety score	.469*	-.379*	-.379*	-.432*	
Trait anxiety score	.737**	-.374*	-.374*	-.354	.747**

\*Correlation is significant at 0.05 level; \*\* Correlation is significant at 0.01 level; BDI = Beck Depression Inventory

Among caregivers according to BDI score 12 (20.7%) were not depressed, 28 (47.3%) were dysphoric and 18 (31%) were depressed. While we compared the use of different coping

methods in these groups, fewer depressed parents used more coping skills though one-way Analysis of Variance (ANOVA) showed this difference was not significant (Table 5).

**Table 5. Use of coping skill and level of depression**

	0-BDI<10 n=12 1-BDI=10-20 n=28 2- BDI=>20 n=18	Mean	Standard deviation	Degree of freedom	F	Significant level
CHIP* I	0 1 2	29.33 26.00 24.67	3.204 1.664 5.523	2	3.157	.059
CHIP* II	0 1 2	25.50 19.93 18.22	6.317 5.225 7.496	2	2.595	.094
CHIP* III	0 1 2	12.50 11.79 10.89	1.049 2.007 2.205	2	1.318	.285

CHIP\* = Coping Health Inventory for Parents

## Discussion

Coping pattern I is composed of 19 behavior items that centered around family life and relationships and the parent's outlook on life and the affected child. Coping pattern II is composed of 18 behavior items that focus on the parents' efforts to maintain a sense of their own 'well-being' through social relationships, involvement in activities that have the potential of enhancing one's self-esteem and doing things to manage psychological tension and strains. Coping pattern III is composed of eight behavior items that focus on relationships between other parents with ill child and the medical staff and its program. It includes behavior directed at understanding and mastering the medical information needed to care the ill child and use the medical equipment in home [10].

One important finding of our study was our study group used less coping strategies. Poor coping skill may arise from many causes. Many depend on the personality type, e.g. an inhibited anxious temperament, having the lower drive to socialize or being rigid, inflexible and intolerant of change. Being poor or having low or no formal education may hinder coping with situation effectively. Taanila A et al in 2001 assessed coping mechanism in parents of physically and/ or intellectually disabled children. They found that 'information and acceptance' were the most effective method of coping. The parents in the high-coping group were of the opinion that they had been informed well about their child's diagnosis and treatment, and they themselves had sought information actively to

cope in the stressful situation. The parents felt that a realistic outlook of the child's disability and acceptance of the situation had helped them cope [13]. We think our patients lack in this area. Due to lack of information from medical system and/or low education level, they are unable to get the holistic picture about the nature, status and outcome of the treatment. The same study noted that the high-coping group had very extensive formal and informal social support networks, whereas the networks in the low-coping group were very small and mainly formal. In our case also coping behavior II, which includes support (maintaining social support, self-esteem and psychological stability), was used less by our patients. The social support groups of parents have not come up as a means of a successful way of coping because these social groups are not available locally. Our patients and family members travel a considerable amount of distance to avail this treatment. Therefore, investing further time becomes impractical. So, it can be inferred that lack of exposure resulted in failure to adopt this coping mechanism.

Our cross-sectional study tried to identify different coping patterns that parents recognize as helpful to them in adapting to the stress and strains associated with managing family life involving a child with cancer. Seven of the top ten coping strategies used by mothers were related to positive definition of the situation and strengthening family life (coping pattern, I). Nature of those statements shows that mother's coping pattern plays a major part in encouraging family members to be concerned, helpful and supportive of each other and in

encouraging members to act openly and to express their feelings directly. This finding is supported by a study by Evangelia Patistea in 2005 in which she studied the coping behavior of parents of children with ALL. They also noted that parental coping styles in childhood cancer primarily focus on preserving and empowering a cohesive family structure. Increased emotional bonding can help the family realize its strengths and become more self-reliant and stronger as a unit. These strategies seem to enable parents to maintain their hope while coping with the demands of living with a child having leukaemia [14].

In our study group coping, behavior II and III (support and medical subscale) didn't help the mothers much which means parents didn't use social support and didn't try to understand the medical situation through communication with other parents or medical professionals. In a similar study in Korea, the finding was that mothers of children with cancer had deficient coping, particularly in support-seeking. One possibility might be that mothers may have chosen to withdraw from social interactions in response to the child's illness that required constant vigilance and care [15]. Evidence seems consistent to suggest that the existence of a child's disability tends to return the family to the traditional pattern of gender relations with mothers taking more responsibility in the medical referral process, being responsible for the child's behavior, and dealing with the child's educational problems. Another relevant explanation might be that at least one dominant coping pattern (e.g. coping pattern, I) was already taking an effect, while confusion in information gathering was stressful. Again, the medical support subscale has been unhelpful because of lack of awareness among patient's family members and lack of education. In a study of coping behavior of Indian wives with alcoholic husbands, it was noted that avoidance was the most commonly endorsed coping behavior [16]. Drawing from this finding it can be said that due to lack of knowledge and understanding the medical support subscale has been avoided by parents.

Most of our patients were either dysphoric or depressed and although statistically not significant, fewer depressed patients used

more coping skill specially pattern I. Undoubtedly, this is an important finding because childhood cancer has social or psychological consequences that at times may be more serious and debilitating than the physical illness itself, an understanding of parental appraisal and coping is of great significance. Limitations of our study included small sample size and lacking a control group. A qualitative study in this area would be beneficial in exploring other coping mechanisms which the study group may use.

Educate the parents about healthy coping mechanism can be a good way to reduce stress in them. To reduce overwhelming worry for the child's life and well-being, health care professionals need to inform parents that most pediatric cancers are now curable with contemporary treatment protocols. However, at the same time, they should acknowledge the possible long-term complications as observed in clinical oncology and described in the literature, and be aware that the helpfulness of information as a coping strategy has received low ratings in oncology studies [17], especially among parents who perceive that the child's disease does not cause much difficulty [18]. Educate patient about the positive effects of having a good social support may be a good option to combat stress and anxiety in them. Building up social support groups at the treatment centre itself can enhance the likelihood of accepting it as a coping mechanism.

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