Burden of caregiving and its impact in the patients of acute lymphoblastic leukemia

Aim: This study aims to study the caregiver burden and its correlates among the caregivers of adolescent and adult patients of acute lymphoblastic leukemia (ALL). Materials and Methods: Sixty caregivers of patients with ALL were assessed on Family Burden Interview Schedule (FBI), Caregiver Strain Index, multidimensional aspect of perceived social support scale, Cognitive–Behavioral Avoidance Scale, ways of coping checklist, and General Health Questionnaire. Results: Caregivers of patients with ALL reported high caregiver burden (FBI objective burden score – 21.77; subjective burden score – 1.83). Among the domains of FBI, the highest burden was seen in the form of financial burden closely followed by disruption of family leisure. Caregivers of male patients and those belonging to higher socioeconomic status reported higher level of objective burden. Caregiver burden was higher among caregivers who reported lower perceived social support, who more often used avoidance and escape as coping and less often used planful problem solving. Higher caregiver burden is associated with higher psychological morbidity. Conclusion: Caregivers of patients with ALL experience high level of caregiver burden and it is associated with lower social support and more often use maladaptive coping strategies.

Keywords: Acute lymphoblastic leukemia, burden, caregivers, correlates

Among various malignant diseases, acute lymphoblastic leukemia (ALL) appears to directly threaten life due to the remarkably rapid course of illness. Although exciting, the success story for ALL comes at the cost of demanding and invasive treatment protocols. The length, usually extending over 2–3 years, is a distinguishing feature of such protocols.

During this difficult and lengthy treatment period, patients rely heavily on the support of their families. For the caregivers, the intensive treatment creates additional fears and challenges. Caregivers frequently assist the patients in the activities of daily living (ADL), administering medications, providing transportation, preparing meals, managing finances, advocating for health care, and providing emotional support. In addition, caregivers have to deal with the procedures of informed consent, hospitalization and repeated visits to the clinic, considerable financial expenses, and the disruption of family routine. For the caregivers of these patients, treatment involves emotional as well as physical burden in addition to the threat of loss. Such caregivers have to accept the complexities of treatment without any guarantee that it will cure the disease. It is now acknowledged that family caregivers provide a vital service to society, and yet, little help is offered to caregivers as they struggle to fulfill their roles.

Evidence suggests that caregiving in patients with ALL, especially children is associated with health problems, alcohol abuse, social withdrawal, sexual and marital difficulties, and problems at work among the

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caregivers. Data also suggest aggravation of already existing interpersonal problems and more disharmonies although there is no evidence of actual increase in divorce in these couples. Data also suggest that about one-fourth to one-fifth of the mothers of patients with acute leukemia experience posttraumatic stress disorder which persists over the period of 2 years. In addition, many mothers reported symptoms of depression, anxiety, and somatization. Data also suggest an association between poor quality of life (QOL) among the caregivers of cancer patients and caregiving burden. Family caregivers of leukemia patients regard caregiving burden as the most influential factor for their QOL. On the other hand, studies suggest that more frequent use of adaptive coping pattern, maintaining family integration and an optimistic outlook for the situation, and less frequent use of maladaptive coping pattern and information seeking are significantly associated with lower psychological distress and better family relationship.

Although family forms the backbone of support in a collectivistic society like India, family caregivers have received very little attention in published literature from India. Some of the studies have evaluated the caregiver burden, and these suggest that majority of parents of children with ALL report burden on various aspects, with 83% of parents of ALL reporting financial burden, 83% reporting disruption of family routine, 61% reported disruption on the family leisure time, 61% reported impact on family interaction, and 65% reported impact on their mental health. Overall, 91% of caregivers experienced burden and 91% of caregivers reported subjective burden. Another study showed that 90% of parents of children with leukemia expressed doubts regarding the accuracy of diagnosis and parents expressed significant financial and social burden on the family. Studies which have evaluated psychological morbidity among parents of children with ALL suggest that half of the parents have psychiatric disorders, namely neurotic depression (36.7%) and adjustment disorder with depressed mood (13.3%). These disorders were of mild to moderate severity and were perceived to be highly treatable.

As is evident from this brief review of data, although there are studies which have evaluated caregiver burden, psychological morbidity, coping, and distress among caregivers/parents of patients with ALL, these studies have not attempted to comprehensively assess all the factors associated with caregiver burden. In this background, this study aims to study the caregiver burden and its correlates among the caregivers of adolescent and adult patients of ALL. It is expected that results of this study will provide better insight into the caregiving experience in relation to malignancies in general and ALL in particular.

### MATERIALS AND METHODS

This study was carried out in the hematology unit of a tertiary care hospital. The study was approved by the Institute Ethics Committee. For this study, 60 patients and caregivers were recruited after obtaining written informed consent. To be included in the study, the patients were required to be diagnosed with ALL for at least 3 months and aged more than 12 years. The caregivers were required to be aged more than 18 years and able to read Hindi and/or English. A caregiver was defined as a person who has been living with the patient and has been intimately involved in the care of the patient since the time of diagnosis, i.e., looking after his/her daily needs, supervising the medications, bringing the patient to the hospital, staying with the patient during inpatient stay, and maintaining liaison with the hospital staff. In addition, caregivers were required to be free from any diagnosed psychiatric disorder and not involved concurrently in the care of any other ill relative.

The caregiving experience was evaluated in the form of caregiver burden by using Family Burden Interview Schedule (FBI) and Caregiver Strain Index (CSI). Other assessments included assessment of social support using multidimensional aspect of perceived social support scale, coping strategies using Cognitive–Behavioral Avoidance Scale (CBAS) and ways of coping checklist (WCC) and psychological morbidity using General Health Questionnaire (GHQ-12).

FBI is a comprehensive semi-structured interview schedule. It is one of the most widely used instruments to assess burden in India among the caregivers of patients with various mental disorders and other physical illnesses. Consists of 24 items grouped under six areas (financial burden, disruption of routine family activities, disruption of family leisure, disruption of family interaction, effect on physical health of others, and effect on mental health of others). Each item is rated on a 3-point scale: zero indicating no burden, a score of 1 indicating moderate, and a score of 2 indicating severe burden. The total score obtained for these six domains is termed as objective burden. After completing the interview, a global rating of the family burden is done by the clinician. The reliability and validity are more than 0.87 and 0.72, respectively. If total score of 24 items is more than 12, it is considered to be severe burden.

CSI was developed by Sullivan and validated by Robinson in 1983. It is a brief, easy, and self-administered instrument. It comprises of 13 questions that measure strain related to care provision. Factor loads of items included in the scale determined by Robinson include
inconvenience, emotional adjustment, adjustment, upsetting, and work adjustment. Positive responses to seven or more items on the CSI indicate a higher level of caregiver strain. This instrument can be used to assess individuals of any age who have assumed the role of caregiver. The tool is limited by lack of a corresponding subjective rating of caregiving impact. Internal consistency and reliability are high (alpha = 0.86) for the scale.

Multidimensional aspect of perceived social support scale consists of 12 items. The scale is divided into 3 subscales on the source of support (family, friends, and a special person), each group consisting of 4 items. Each item is rated using a 7 range scale varying between “definitely no” and “definitely yes.” The reliability and the internal consistencies of the scale and the subscales are high; the test–retest reliability over a 2–3-month period produces correlations ranging from 0.72 to 0.85.

The CBAS is a self-report measure intended to assess multiple dimensions of trait-level avoidance. The scale has 31 items, each rated on a 4-point Likert scale, and is comprised of four subscales of avoidance: behavioral social, cognitive social, behavioral nonsocial, and cognitive nonsocial avoidance. Subscales have adequate to strong coefficient alphas (α = 0.86, 0.78, 0.75, 0.80, respectively) and test–retest reliability (r = 0.86, 0.58, 0.88, 0.94, respectively). A total avoidance score can also be calculated, which has excellent internal consistency (α = 0.91) and test–retest reliability (0.92). The CBAS also correlates moderately with other measures of avoidance as well as depression and anxiety scales.

WCC consists of 66 items where each item has a brief description of a cognitive and behavioral strategy for coping with stressful events. The responder is asked to keep a specific stressful situation in mind that he/she may have experienced in the past week. The specific situation may have involved one’s family, job, friends, or something else important to the person. Rating is done on a 4-point scale with higher scores indicating more frequent use of that particular strategy by the individual while dealing with the specific stressful situation. The 66 items are grouped into 8 coping subscales, namely confrontive coping, distancing, self-controlling, seeking social support, accepting responsibility, escape avoidance, planful problem solving, and positive reappraisal. The score on each subscale is obtained by addition of the item scores. This checklist has high reliability with Cronbach’s alpha (α) score of 0.89.

The 12-item Hindi version of GHQ-12 is a very popular screening measure in primary care and community setting. Each item is noted on a 2-point scale. A score of <2 indicates that the individual is free from any psychiatric illness. Caregivers scoring more than 2 on GHQ were advised to seek a formal psychiatry consultation.

Patients will ALL were assessed on Katz Index of Independence in ADL, commonly referred to as the Katz ADL. It assesses the functional status in the form of a person’s ability to perform ADL independently. The index ranks adequacy of performance in the six functions of bathing, dressing, toileting, transferring, continence, and feeding. Clients are scored yes/no for independence in each of the six functions. A score of 6 indicates full function, 4 indicates moderate impairment, and 2 or less indicates severe functional impairment. The tool is used extensively as a flag signaling functional capabilities.

**Statistical analysis**

Descriptive analysis was carried out using mean and standard deviation (SD) with range for continuous variables. Frequency and percentages were determined for categorical variables. Correlations were studied using Pearson correlation coefficient and Spearman’s rank correlation. Comparisons were done using Chi-square test, Fisher’s exact test, t-test, and Mann–Whitney U-test. In view of the multiple correlations, for all statistical analyses, P ≤ 0.001 was considered as statistically significant.

**Sociodemographic profile of the study sample**

The sociodemographic details of the patients and the caregivers are shown in Table 1. The mean age of patients was about 26 years (SD 11.55; range 14–65; median 23). Majority of the patients were males, married, educated beyond Matriculation from nonnuclear families, Hindu by religion, and belonged to the middle socioeconomic class. There was nearly equal distribution of patients from urban/rural locality. The mean number of years of education of patients was 11.57 years (SD 3.16), and mean monthly family income was rupees 15,900 (SD 24,812.43). Majority of the patients were not on any paid employment. The caregivers were middle aged, mostly male, and married. More than half of the caregivers were parents (58.3%). Caregivers were spending most part of the day in taking care of the patient and were taking care of the patient for the past 11 months (SD 8.82; range 1–48).

**Clinical profile of the patient group**

The mean duration of symptom before their first visit to the hospital was 7.28 (SD = 8.73) months. In terms of symptoms at presentation, almost all patients had pallor and about half of them had splenomegaly [Table 2]. In terms of previous treatment for ALL, majority of the patients had received prednisolone (85%), vincristine (75%), cyclophosphamide (71.7%), methotrexate (71.7%), daunorubicin (70%), and cytarabine (63.3%). More than two-third (70%) of patients had been given other
medications such as granulocyte colony-stimulating factor (CSF) and granulocyte macrophage-CSF. In terms of side effects experienced with various chemotherapeutic agents, all patients had nausea and more than 90% among them had vomiting (91.7%) after receiving chemotherapeutic agents in the past. About 92% patients also had hair loss (91.7%). Less than half of the study participants had also experienced anorexia (41.7%) and fatigue (41.7%). At the time of assessment, about three-fourth of the patients had restricted activity of daily living at the time of the assessment. The Katz index score was 5.88 (SD = 0.64), indicating severe restriction in functionality. In terms of current medications, about three-fourth were receiving prednisolone and two-third were receiving methotrexate. One-third of the patients were receiving cytarabine, vincristine, and 6-mercaptopurine. In terms of supportive management, about half were receiving vitamin supplements and one-third were receiving antibiotics [Table 2].

### Table 1: Sociodemographic profile of the patient group

| Sociodemographic variables                  | Mean (SD)/n(%)  |
|---------------------------------------------|-----------------|
| Age (years), range                          | 26.02 (11.55), 42.37 (11.25), 14-65, 22-65 |
| Gender, n (%)                               | Male 37 (61.7), Female 23 (38.3) |
| Current marital status, n (%)               | Currently married 34 (56.7), Currently unmarried 26 (43.3) |
| Education - number of years, range          | 11.57 (3.16), 10.28 (5.01), 4-18, 0-24 |
| Education, n (%)                            | Up to matric 24 (40.0), Above matric 36 (60.0) |
| Occupation, n (%)                           | Paid employment 17 (28.3), Others (unemployed/student/retired/homemaker) 43 (71.7) |
| Socioeconomic status, n (%)                 | Lower 23 (38.3), Middle 34 (56.6), Upper >2 3 (5.0) |
| Family income (rupees per month), range     | 15,907 (24,812.43), 0-175,000 |
| Religion, n (%)                             | Hindu 38 (63.3), Non-Hindu 22 (36.7) |
| Family type, n (%)                          | Nuclear 34 (56.7), Nonnuclear 26 (43.3) |
| Locality, n (%)                             | Urban 29 (48.3), Rural 31 (51.7) |
| Relationships with patient, n (%)           | Parents 35 (58.3), Spouses 17 (28.3), Others* 8 (13.3) |
| Hours of time spent/day, range              | 14.1 (2.97), 2-16 |
| Time since caregiver in months, range       | 11.33 (8.82), 1-48 |

### Table 2: Clinical profile of the patients

| Variables                                | Mean (SD)/n(%)  |
|------------------------------------------|-----------------|
| Symptom duration (months), mean (SD), range | 7.28 (8.73), 0-48 |
| Examination findings at the time of presentation, frequency (%) | Pallor 58 (96.7), Splenomegaly 32 (51.7), Hepatomegaly 26 (43.3), Lymphadenopathy 25 (41.7), Febrile 20 (33.3), Tachypnea 13 (21.7) |
| Activity level of patient*, frequency (%) | Mobile 15 (25.0), Restricted activity 43 (71.7), Dependent on others for bathing/toileting 2 (3.3) |
| Total score of Katz index, mean (SD), range | 5.88 (0.64), 2-6 |
| Current medication, frequency (%)        | Prednisolone 45 (76.7), Daunorubicin 7 (11.7), Etoposide 5 (8.3), Cyclophosphamide 15 (25), Cytarabine 22 (36.7), Vincristine 20 (33.3), L-asparagine 1 (1.7), 6-mercaptopurine 22 (36.7), Imatinib 1 (1.7), Methotrexate 38 (63.3), Antibiotic 20 (33.3) |
| Vitamin supplementation                   | 33 (55) |

*Other caregivers include 3 brothers, 2 sons, 1 daughter, and 1 grandfather.

SD - Standard deviation

In terms of side effects experienced with various chemotherapeutic agents, all patients had nausea and more than 90% among them had vomiting (91.7%) after receiving chemotherapeutic agents in the past. About 92% patients also had hair loss (91.7%). Less than half of the study participants had also experienced anorexia (41.7%) and fatigue (41.7%). At the time of assessment, about three-fourth of the patients had restricted activity of daily living at the time of the assessment. The Katz index score was 5.88 (SD = 0.64), indicating severe restriction in functionality. In terms of current medications, about three-fourth were receiving prednisolone and two-third were receiving methotrexate. One-third of the patients were receiving cytarabine, vincristine, and 6-mercaptopurine. In terms of supportive management, about half were receiving vitamin supplements and one-third were receiving antibiotics [Table 2].

### Caregiving: Impact on the caregivers

Mean scores obtained on FBI, CSI, MPSS, CBAS, WCC, and GHQ-12 are shown in Table 3. On FBI, maximum burden was perceived in the domain of financial burden and least burden on “effect on physical health of others.” In terms of total objective burden, most of the caregivers (91.7%) reported severe burden. On CSI, more than three-fourth of caregivers scored 7 or more on the CSI, which indicate significant caregiver strain. In terms of amount of social support, half of the caregivers reported having moderate level of social support. As per CBAS, nonsocial avoidance coping was used slightly more frequently than social avoidance score. On WCC, the mean weighted score was highest for the domain of seeking social
Table 3: Impact on the caregivers

| Variables                        | Mean (SD) | Weighted mean scoresa |
|----------------------------------|-----------|-----------------------|
| **FBI**                          |           |                       |
| Financial burden                 | 7.67 (2.71)| 1.28 (0.45)           |
| Disruption of routine family activities | 6.08 (2.55)| 0.87 (0.36)           |
| Disruption of family leisure     | 4.95 (2.42)| 1.24 (0.61)           |
| Disruption of family interaction | 1.41 (1.33)| 0.47 (0.44)           |
| Effect on physical health of others | 0.63 (1.07)| 0.32 (0.54)           |
| Effect on mental health of others | 1.01 (0.65)| 0.51 (0.33)           |
| Total objective burden           | 23.77 (7.12)| 0.91 (0.30)           |
| Subjective burden                | 1.83 (0.53)| 1.83 (0.53)           |
| Subjective burden (%)            |           |                       |
| No burden                        | 4 (6.7)   |                       |
| Moderate burden                  | 2 (3.3)   |                       |
| Severe burden                    | 54 (90)   |                       |
| FBI total burden score (>12)     | 55 (91.7) |                       |
| **CSI**                          |           |                       |
| Inconvenience                    | 3.78 (0.22)| 0.63 (0.20)           |
| Adjustment                       | 2.80 (0.48)| 0.37 (0.27)           |
| Work adjustment                  | 0.75 (0.45)| 0.93 (0.16)           |
| Upsetting                        | 0.33 (0.54)| 0.75 (0.44)           |
| Total CSI score                  | 7.85 (1.84)| 0.61 (0.14)           |
| Total CSI score (≥7)             | 46 (76.7) |                       |
| **MPSS**                         |           |                       |
| Friends' social support          | 16.82 (4.70)| 4.20 (1.17)           |
| Family social support            | 22.00 (4.93)| 4.61 (1.32)           |
| Significant others' social support | 18.43 (5.29)| 5.5 (1.23)           |
| Total MPSS score                 | 57.25 (11.16)| 4.77 (0.93)          |
| Level of perceived support (%)   |           |                       |
| Low acuity (12–48)              | 15 (25)   |                       |
| Moderate acuity (49–68)          | 31 (51.7) |                       |
| High acuity (69–84)              | 14 (23.3) |                       |
| **CBAS**                         |           |                       |
| Cognitive social avoidance       | 14.27 (4.39)| 2.03 (0.63)           |
| Cognitive nonsocial avoidance    | 18.82 (7.28)| 1.88 (0.73)           |
| Behavior social avoidance        | 14.82 (4.28)| 1.85 (0.53)           |
| Behavior nonsocial avoidance     | 12.37 (3.40)| 2.06 (0.57)           |
| Nonsocial avoidance total        | 31.18 (10.07)| 1.95 (0.63)          |
| Social avoidance total           | 29.08 (7.93)| 1.92 (0.53)           |
| Total CBAS score                 | 60.27 (17.24)| 1.94 (0.56)          |
| **WCC**                          |           |                       |
| Escaping avoidance coping         | 16.75 (4.43)| 2.09 (0.55)           |
| Distancing coping                | 12.97 (2.82)| 2.16 (0.47)           |
| Confrontive coping               | 11.92 (2.04)| 1.99 (0.34)           |
| Self-controlling coping          | 15.88 (2.46)| 2.27 (0.35)           |
| Seeking social support           | 16.87 (3.17)| 2.81 (0.53)           |
| Acceptability responsibility coping | 6.52 (1.93)| 1.63 (0.48)           |
| Planful problem solving coping   | 14.18 (2.80)| 2.36 (0.47)           |
| Positive appraisal coping        | 13.95 (2.91)| 2.00 (0.42)           |
| **GHQ-12**                       |           |                       |
| Total score                      | 4.1 (3.62) | 0.34 (0.30)           |
| ≥2 (%)                           | 42 (70)   |                       |

*Weighted scores were calculated by dividing the total score for the particular domain by number of items included in that domain. FBI - Family Burden Interview Schedule; CSI - Caregiver Strain Index; MPSS - Multidimensional aspect of perceived social support; CBAS - Cognitive-Behavioral Avoidance Scale; WCC - Ways of coping checklist; GHQ-12 - General Health Questionnaire-12

Correlates of caregiver burden

Only few associations emerged between FBI and demographic variables. Caregivers of male patients reported significantly higher financial burden (male: 8.51 [SD – 2.38] versus female: 6.30 [2.72]; t-value 3.31, P = 0.001and total subjective burden (male: 1.90 [SD – 0.4] versus female: 1.73 [0.69]; t-value 3.00, P < 0.001). Caregivers from higher socioeconomic status (middle/high) reported more disruption of routine family activities on FBI (middle/high: 6.81 [SD 2.53] vs. lower: 4.91 [2.71]; t-value 2.98, P < 0.001) and higher total objective burden (middle/high: 24.03 [SD 6.69] vs. lower: 18.13 [6.37]; t-value 3.38, P = 0.001).

There were no significant association between demographic variables of caregivers with FBI. Similarly, there were no significant association between demographic variables of the patients and caregivers with CSI. Caregiver relationship with patient also did not have any significant impact on the FBI and CSI scores. Patient's clinical variables including activity level did not have any significant impact on FBI and CSI scores.

When the correlations of burden with social support were evaluated, as depicted in Table 4, low social support was associated with significantly higher objective and subjective burden as assessed using FBI. In terms of various domain of objective burden, lower social support had significant correlation with financial burden, disruption of routine activities, disruption of family leisure, and disruption of family interaction. Lower social support was also associated with higher total CSI score.

Association of burden with coping

Higher use of avoidance coping (both social and nonsocial) was associated with significantly higher total objective burden and some of the domains of objective burden. However, no correlation was seen between avoidance coping and total subjective burden except for positive correlation between subjective burden cognitive nonsocial avoidance component of CBAS. In terms of CSI, higher use of avoidance coping (both social and nonsocial) except for behavior social avoidance was associated with significantly higher burden as assessed by CSI total score. However, there were only occasional correlations, between component of CSI and CBAS (Table 5).
**DISCUSSION**

Rarely do people go through the cancer experience alone. In fact, cancer is referred to as a disease affecting the family who travel the cancer journey together.

Dubbed the “hidden sufferers” within the cancer experience, family members are doubly vulnerable because they have to face the patient’s emotional reaction as well as their own. Sometimes, caregiving takes a serious and significant physical and psychological toll. It is important to recognize that caregivers typically put the needs of their loved ones before their own needs, and when providing complex care for an extended period of time, they are at increased health risk, because of the limited time to rest, engage in self-care activities, or to seek medical help when they need it. Caregivers providing higher levels of support often postpone or neglect their own needs and are even often required to give up their usual daily activities due to their caregiving responsibilities.

These efforts to care for their loved ones lead to significant burden on the family caregivers. This burden is expected to be more in case of ALL, due to long-term, intensive, and expensive treatment with considerable side effects. Although some of the studies have evaluated the caregiver burden among the caregivers of patients with ALL, very few studies have evaluated its correlates. Further these studies have focused on only one or two correlates in the form of social support, coping, and psychological morbidity, but none of the studies have evaluated all these variables together. Accordingly, it can be said that there is lack of studies which have comprehensively evaluated the whole caregiving experience of caregivers of patients with ALL. The present study attempted to fill this void.

This study utilized a framework derived from the “stress-appraisal-coping” model of caregiving. Accordingly, it examined various components of this model including burden, coping, social support, and psychological morbidity among caregivers.

In the present study, caregiver burden was assessed using two scales, i.e., FBI and CSI. Two scales were used concurrently to broaden the assessment of caregiver burden. In the present study, the mean FBI objective burden score was 21.77 and mean subjective burden score was 1.83 with 91.7% of the caregivers reporting severe burden. When the findings of the present study are compared with the previous study done among caregivers of children with ALL, it is evident that the level of caregiver burden is the same among caregivers of children and adults with ALL. When the findings of the present study are compared with previous studies which have comprehensively evaluated the whole caregiving experience of caregivers of patients with ALL, very few studies have evaluated its correlates. Further these studies have focused on only one or two correlates in the form of social support, coping, and psychological morbidity, but none of the studies have evaluated all these variables together. Accordingly, it can be said that there is lack of studies which have comprehensively evaluated the whole caregiving experience of caregivers of patients with ALL. The present study attempted to fill this void.

When the relationship of burden was evaluated with WCC, higher use of “escaping” was associated with higher burden in all the domains of FBI and CSI. Higher use of distancing and lower use of planful problem solving as a coping was associated with higher total objective burden. Higher use of distancing as a coping was associated with higher total CSI score.

Use of “confrontative” and “accepting responsibility” as coping was not associated with burden as assessed by FBI and CSI. Higher use of positive appraisal as a coping mechanism was associated with lower burden in the domains of disruption of family interaction.

GHQ total score correlated positively with financial burden, effect on mental health of others, upsetting domain of CSI, and total CSI score.

Table 4: Association of burden and perceived social support

|                        | Friends' social support | Significant others' social support | Family social support | Total MPSS |
|------------------------|------------------------|-----------------------------------|-----------------------|------------|
| FBI                    |                        |                                    |                       |            |
| Financial burden       | −0.47*** (<0.001)      | −0.55*** (<0.001)                 | −0.51*** (<0.001)     |            |
| Disruption of routine family activities | −0.44*** (<0.001)      | −0.45*** (<0.001)                 | 0.45*** (<0.001)      |            |
| Disruption of family leisure | −0.52*** (<0.001)      | −0.43*** (<0.001)                 | −0.43*** (<0.001)     |            |
| Disruption of family interaction | −0.48*** (<0.001)      | −0.35*** (<0.001)                 | 0.45*** (<0.001)      |            |
| FBI total objective burden | −0.46*** (<0.001)      | −0.41*** (<0.001)                 | −0.68*** (<0.001)     |            |
| Subjective burden      | −0.44*** (<0.001)      | −0.41*** (<0.001)                 | −0.68*** (<0.001)     |            |
| CSI                    |                        |                                    |                       |            |
| Inconvenience          | −0.68** (<0.001)       | −0.52** (<0.001)                  | −0.52** (<0.001)      |            |
| Total score of CSI     | −0.60** (<0.001)       | −0.51** (<0.001)                  | −0.51** (<0.001)      |            |

FBI - Family Burden Interview Schedule; CSI - Caregiver Strain Index. *P<0.05; **P<0.01; ***P<0.001; *Spearman Rank Correlation coefficient

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Table 5: Association between coping and general health questionnaire with caregiver burden among caregivers

|                              | FBI | CSI |
|------------------------------|-----|-----|
|                              | Financial burden | Disruption of routine family activities | Disruption of family leisure | Disruption of family interaction | Effect on physical health of others | Effect on mental health of others | Subjective burden | FBI total objective burden | Inconvenience | Adaptation | Overwhelmed | Upsetting | Total score of CSI |
|                              |     |                               |                               |                               |                                 |                                |                         |                           |               |             |             |           |                   |
| CBAS                         |     |                               |                               |                               |                                 |                                |                         |                           |               |             |             |           |                   |
| Cognitive social avoidance   |     |                               |                               |                               |                                 |                                |                         |                           |               |             |             |           |                   |
| Cognitive nonsocial avoidance| 0.45*** |                               |                               |                                 |                                 |                                |                         |                           |               |             |             |           |                   |
| Behavior social avoidance    |     |                               |                               |                               |                                 |                                |                         |                           |               |             |             |           |                   |
| Behavior nonsocial avoidance |     |                               |                               |                                 |                                 |                                |                         |                           |               |             |             |           |                   |
| Nonsocial avoidance total    | 0.41*** | 0.40***                      | 0.42***                      | 0.37***                       |                                 |                                |                         |                           |               |             |             |           |                   |
| Social avoidance total       |     |                               |                               |                                 |                                 |                                |                         |                           |               |             |             |           |                   |
| Total of avoidance           | 0.38*** | 0.39***                      | 0.39***                      |                                 |                                 |                                |                         |                           |               |             |             |           |                   |
| WCC                          |     |                               |                               |                                 |                                 |                                |                         |                           |               |             |             |           |                   |
| Escaping                     | 0.54*** | 0.56***                      | 0.47***                      |                                 |                                 |                                |                         |                           |               |             |             |           |                   |
| Distancing                   | 0.44*** |                               |                               |                                 |                                 |                                |                         |                           |               |             |             |           |                   |
| Confrontive                  | -    | -                             | -                            | -                              | -                               |                                |                         |                           |               |             |             |           |                   |
| Acceptability-responsibility | -    | -                             | -                            | -                              | -                               |                                |                         |                           |               |             |             |           |                   |
| Planful problem solving      | -0.38*** | -0.38***                    | -0.44***                    | -0.44***                      |                                 |                                |                         |                           |               |             |             |           |                   |
| Positive appraisal           | -0.37*** |                               |                               |                                 |                                 |                                |                         |                           |               |             |             |           |                   |
| GHQ                          |     |                               |                               |                                 |                                 |                                |                         |                           |               |             |             |           |                   |
| GHQ total score              | 0.38*** |                               |                               |                                 |                                 |                                |                         |                           |               |             |             |           |                   |

FBI - Family Burden Interview Schedule; CSI - Caregiver Strain Index; CBAS - Cognitive-Behavioral Avoidance Scale; WCC - Ways of coping checklist; GHQ - General Health Questionnaire. *P<0.05; **P<0.01; ***P<0.001
bipolar disorder, obsessive compulsive disorder, and depressive disorder, it is also evident that the caregivers of patients with ALL experience significantly higher level of burden. The higher level of burden among the caregivers of ALL was seen in all the subdomains of objective burden and also in subjective burden. Studies which have evaluated caregiver burden using CSI also suggest that the caregiver burden experienced by the caregivers of patients with ALL is more than other illnesses such as dementia, schizophrenia, and stroke. The high level of caregiver burden experienced by the caregivers of ALL compared to other physical illnesses and psychiatric disorders can be understood from the nature of ALL as an illness, which is ultimately associated with fatal outcome. Accordingly, it can be said that the caregivers of patients with ALL should be given due importance, and the clinicians managing these patients must evaluate the caregiver stress as well as attempt to address their needs too.

When compared with caregivers of female patients, caregivers of male patients reported significantly higher level of financial burden and subjective burden. Higher financial burden among the caregivers of male patients could be due to various reasons. First, the male individuals who suffer from ALL could be the main earning member of the family. Accordingly, diagnosis of ALL leads not only to increase in the outflow of money in the form of treatment expenses but also reduced income. Second, traditionally in Indian culture, male children are valued more than the females. Due to this, very often, families go to any extent to get the male member treated. This in the context of ALL possibly may lead to choosing all the possible chemotherapeutic options, irrespective of the cost, despite relapse on one of the regimen and being explained about the poor prognosis. On similar lines, loss of a male child is always more traumatic when compared to a female child in the Indian culture. This possibly explains the higher subjective burden among the caregivers of male patients.

In the present study, it emerged that poor social support was associated with significantly higher burden in all the domains of FBI except for “effect on mental health of others.” In terms of CSI, poor family support was associated with higher burden in the domains of inconvenience and total CSI score. These findings are consistent with the existing literature which suggests negative correlation between the social support and burden experienced by caregivers of patients with cancers. Accordingly, it can be said that any effort to improve the social support of caregivers of patients with ALL can reduce the caregiver burden.

In terms of coping, this study suggests that higher use of avoidance, escape, and distancing as coping are associated with significantly higher objective burden whereas higher use of planful problem solving and positive appraisal as coping mechanisms are associated with lower objective burden.

Existing literature also suggests that use of adaptive coping mechanisms like positive appraisal is a significant predictor of all adjustment outcomes among caregivers of patients with cancer. The hypothesis that less reliance on avoidant coping would be related to better caregiver adjustment was also supported by the present study. Accordingly, it can be said that the clinicians dealing with the caregivers of patients with ALL must evaluate the coping strategies used by the caregivers and must encourage the use of adaptive coping and discourage the use of maladaptive coping mechanisms to improve the overall caregiving experience.

Higher financial burden and effect on physical health of others were associated with significantly higher psychological morbidity. Previous studies involving the caregivers of patients with various cancers also show positive association between burden and psychological morbidity in the form of symptoms of parent anxiety, depression, and posttraumatic stress. Accordingly, it can be said that reducing the caregiver burden can lead to reduction in the psychological morbidity among the caregivers of patients with ALL.

The present study has certain limitations. The study sample was relatively small, and the assessment of caregivers was cross-sectional. The study involved assessment of patients and caregivers attending a tertiary care hospital. Accordingly, the findings may not be generalized to other populations. Future studies must attempt to overcome the limitations of the present study.

**CONCLUSION**

The present study suggests that caregivers of patients with ALL experience high level of caregiver burden. In terms of caregivers’ own characteristics, those caregivers who more often use maladaptive coping strategies experience higher level of burden. Similarly, those caregivers who have lower social support experience more burden. On the other hand, the presence of higher burden is associated with higher psychological morbidity. Hence, any effort made to reduce the use of maladaptive coping and improvement in social support of caregivers can lead to reduction in caregiver burden. These would also possibly lead to reduction in psychological morbidity among the caregivers.

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