


Caregiver Burden in the Patients of Acute Myeloblastic Leukemia

Sandeep Grover¹  · Kumari Rina¹ · Pankaj Malhotra² · Alka Khadwal²

Received: 14 October 2018 / Accepted: 14 November 2018 / Published online: 3 January 2019
© Indian Society of Hematology and Blood Transfusion 2019

Abstract To study the caregiver burden and its correlates among the caregivers of adolescent and adult subjects with acute myeloblastic leukemia (AML). 30 caregivers of patients with AML were evaluated on family burden interview schedule (FBI), Caregiver Strain Index, multi-dimensional aspect of perceived social support scale, Cognitive-Behavioural Avoidance Scale, ways of coping checklist and General Health Questionnaire. Caregivers of patients with AML reported high caregiver burden (FBI objective burden score: 27.8; subjective burden score: 1.43). Among the various domains of FBI, the mean scores were highest for the domain of disruption of family activities and this was closely followed by disruption of family leisure. Patients with lower family income reported higher subjective and objective burden and were more overwhelmed. Patients belonging to lower socioeconomic status reported more financial 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 acceptability–responsibility and positive appraisal coping. Higher caregiver burden is associated with higher psychological morbidity. Caregivers of subjects with AML experience high level of caregiver burden and it is associated with lower social support and more often use maladaptive coping strategies.

Keywords Acute myeloblastic leukemia · Caregivers · Burden · Correlates

Introduction

Acute myeloid leukemia (AML) is considered to have poor long term survival rates, with only 27.6% of adult AML patients surviving at 5 years [1]. Due to the nature of the illness, patients with AML, rely heavily on their family members. Due to the pressure of caregiving, caregivers of patients with chronic physical and psychiatric disorders often experience adverse psychological, behavioural, and physiological consequences of taking up the caregiver role [2–10]. Family caregivers also encounter issues at their workplace, financial insecurity and financial burden [11, 12]. It is estimated that for average families, compared with a non-caregiving family, out-of pocket expense on treatment is about 2.5 times more (11.2% of income vs. 4.1%) when one of the family members needs help with everyday activities (e.g., bathing, dressing) [13].

Patients with leukemia are in particular need of support and care due to the complications of the disease per se and the side effects associated with chemotherapy [14]. Data suggests that about one-fourth to one-fifth of the mothers of patients with acute leukaemia experience post-traumatic stress disorder which persists over the period of 2 years [15]. Additionally many mothers of children with AML report symptoms of depression, anxiety and somatization [15, 16]. Quality of life (QOL) of family caregivers of leukemia is influenced to a large extent by the caregiving burden [15]. Lower psychological distress and better family relationship have been shown to be associated with maintaining family integration, having an optimistic outlook for the situation, more frequent use of adaptive coping

✉ Sandeep Grover
drsandeepg2002@yahoo.com

¹ Department of Psychiatry, Postgraduate Institute of Medical Education and Research, Chandigarh 160012, India

² Department of Hematology, Postgraduate Institute of Medical Education and Research, Chandigarh 160012, India

pattern and information-seeking coping and less frequent use of maladaptive coping pattern [17, 18]. Among the various types of burden, financial burden has been shown to be a major impediment in taking treatment [19] and remission phase is considered as the most emotionally challenging phase [20].

Little information is available in terms of caregiver burden of patients with AML. In this background this study aimed to evaluate the caregiver burden among the caregivers of adolescent and adult patients of AML. An attempt was also made to study the association of caregiver burden with social support, coping and psychological morbidity among the caregivers.

Materials and Methods

This study was carried out in the Haematology unit of a tertiary care hospital. For this study 30 consecutive newly diagnosed patients with AML and their primary caregivers were recruited after seeking written informed consent.

As per the inclusion criteria of the study, the patients were required to be diagnosed with AML and aged more than 12 years. The caregivers were required to be aged ≥ 18 years and able to read Hindi and/or English. Person was considered as the caregiver, if they were residing with the patient and were closely involved in the care of the patient since the time of diagnosis, i.e., looking after daily needs, supervising the medications, maintaining liaison with the treatment team, accompanying the patient to the outpatient visits and staying with the patient during the period of hospitalization. Additionally, caregivers were required to be free from any diagnosed mental 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) [21] and Caregiver Strain Index (CSI) [22, 23]. Social support was assessed by using Multidimensional aspect of Perceived Social Support scale [24]. Coping was assessed by using Cognitive-Behavioural Avoidance Scale [25, 26] and ways of coping checklist [27] and psychological morbidity among caregivers was assessed by using General Health Questionnaire [28].

FBI is a semi-structured interview schedule [21]. It consists of 24 items grouped under six areas. Each item is rated on a 3-point scale: 0 indicating no burden and a score of 2 indicating severe burden. These are measures of objective burden. Total score of more than 12 is considered to be an indicator of severe burden.

CSI a self administered instrument comprising 13-questions that measures strain related to caregiving.

Positive responses to ≥ 7 on the CSI suggests higher caregiver strain [22, 23].

Multidimensional aspect of perceived social support scale [24] consists of 12 items. Each item is rated on a 7 point scale varying between “definitely no” and “definitely yes”. The scale is divided into 3 subscales on the source of support (family, friends and a special person), each group consisting of 4 items. The scale has adequate psychometric properties in the form of high reliability, high internal consistency and test-retest reliability [24].

The Cognitive-Behavioural Avoidance Scale (CBAS) [25] is a self-report instrument which assesses trait-level avoidance. The scale has 31 items, each rated on a 4 point Likert scale. Various items of the scale are grouped into four subscales of avoidance: Behavioral Social, Cognitive Social, Behavioral Non-social, and Cognitive Non-social avoidance. All the subscales have high coefficient alphas ($\alpha = 0.86, 0.78, 0.75, 0.80$, respectively) and test-retest reliability ($r = 0.86, 0.58, 0.88, 0.94$, respectively).

Ways of coping checklist (WCC) [26, 27], is a 66 items scale, each item of which provide a brief description of a cognitive and behavioural coping strategy to deal with stressful events. Rating is based on the experiences of last 1 week. Each item is rated on a 4-point scale with higher scores indicating more frequent use of that particular strategy. The scale has 8 coping subscales which are determined by addition of the item scores.

The 12 item Hindi version [28] of General Health Questionnaire (GHQ-12) [29] is a very popular measure to screen psychological morbidity. A score of < 2 indicates absence of psychological distress. In the present study, caregivers who scored ≥ 2 on GHQ were told to seek a formal psychiatry consultation.

Katz Index of Independence in Activities of Daily Living (ADL) [30, 31] assesses a person’s ability to carry out activities of daily living independently. The scale covers six basic function, i.e., bathing, dressing, toileting, transferring, continence, and feeding.

For this study, participants were contacted during their routine visit to the hospital. They were explained about the study and those who agreed to participate were induced into the study after obtaining written informed consent. All the assessments were completed over one session by a trainee psychiatrist.

Descriptive analysis involved computation of mean and standard deviation with range for continuous variables and frequencies and percentages for categorical variables. Correlations were studied by using Pearson correlation coefficient and Spearman’s rank correlation. In view of the multiple correlations, only the correlations which were significant at the $p \leq 0.001$ were considered as statistically significant.

Results

Socio-demographic Profile of the Study Sample

The mean age of patients was about 40.7 years (SD 14.3; range 12–66; Median 41). Majority of the patients were female (56.7%), married (80%), educated beyond matriculation (66.7%), from urban locality (56.7%) and belonged to the middle socioeconomic class (76.7%). The mean duration of formal education in years for patients was 12.33 years (SD 4.80) and mean family income per month was Rupees 54,650 (SD 43965). Majority (56.7%) of the patients were not on paid employment.

The caregivers were middle aged (42.4 years, SD 11.3), mostly male (56.7%) and married (86.7%). Caregivers were spending most part of the day in taking care of the patient (mean: 14.5 h; SD 2.6; range 7–18).

Clinical Profile of the Patient Group

The mean duration of symptom prior to their first visit to the hospital was 4.58 (SD 2.53) months. Other clinical details are provided in Table 1. The KATZ index score was 4.83 (SD 1.51), indicating severe restriction in functionality.

Caregiving: Impact on the Caregivers

Details of the impact on the caregivers is depicted in Table 2.

Correlates of Caregiver Burden

On FBI, younger the patient, higher was the score in the domain of “effect of mental health of others”. Caregivers of the patients with low family income reported more financial burden, disruption in family interaction, effect on physical health of others and subjective and objective burden. Those who were from middle or low socio-economic status reported more financial burden (p value = .05). Married caregivers reported more disruption of family leisure than unmarried caregivers ($p < 0.001$). Those caregivers who were spending more time with the patient had more disruption of routine family leisure and reported more subjective burden (p value 0.03). Female caregivers reported more “effect on mental health of others” ($p = 0.04$).

On CSI, caregivers of the patients with low family income had high total CSI score. Caregivers of female patients scored more in the domain “overwhelmed” ($p < 0.001$). Caregivers of married patients had higher score in the domain of “inconvenience” (p value .05)];

Table 1 Clinical profile of the patients

| Variable | Mean (SD) |
|---|-------------------------|
| Symptom duration (in months) | 4.58 (2.53) [Range 1–9] |
| Examination findings at the time of presentation | Frequency (percentage) |
| Pallor | 30 (100%) |
| Splenomegaly | 6 (20%) |
| Hepatomegaly | 13 (43.3%) |
| Lymphadenopathy | 6 (20%) |
| Febrile | 27 (90%) |
| Tachypnoea | 24 (80%) |
| Pneumonia | 0 (0%) |
| Central line | 9 (30%) |
| Moist oxygen | 2 (6.7%) |
| <i>Examination finding at the time of interview</i> | |
| Febrile ^a | 10 (33.3%) |
| Tachypnoea ^b | 9 (30.0%) |
| <i>Activity level of patient^c</i> | |
| Mobile | 1 (3.3%) |
| Restricted activity | 18 (60%) |
| Dependent on others for bathing/toileting | 7 (23.3%) |
| Bedridden | 4 (13.3%) |
| Total score of KATZ Index | 4.83 (1.51) [range 1–6] |
| <i>Current medication</i> | |
| Prednisolone | 2 (6.7%) |
| Daunorubicin | 5 (16.7%) |
| Etoposide | 1 (3.3%) |
| Cyclophosphamide | 0 (0%) |
| Cytarabine | 4 (13.8%) |
| Vincristine | 1 (3.3%) |
| L-asparaginase | 1 (3.3%) |
| 6-Mercaptopurine | 1 (3.3%) |
| Imatinib | 1 (3.3%) |
| Methotrexate | 1 (3.3%) |
| Antibiotic | 30 (100%) |
| Vitamin supplementation | 30 (100%) |

^aFebrile, i.e. fever was defined as axillary temperature more than 102.2°F

^bTachypnoea was defined as respiratory rate more than 18 per minute

^cMeasured on KATZ index of activity of daily living

“overwhelmed” (p value .04)] and total CSI score (p value .05) than caregivers of unmarried patients. Male caregivers scored higher in the domain of “adaptation” (p value .03)] and “overwhelmed” (p value $< .001$). In terms of activity level, more restricted the activity of the patient more “upsetting” it was for the caregivers.

Table 2 Caregiver burden, perceived social support and coping

| Variable | Mean (SD) | Weighted mean scores ^a |
|---|---------------|-----------------------------------|
| <i>Family burden interview schedule (FBI)</i> | | |
| Financial burden | 7.5 (3.07) | 1.25 (.51) |
| Disruption of routine family activities | 8.09 (1.60) | 1.27 (.23) |
| Disruption of family leisure | 7.57 (.63) | 1.89 (.16) |
| Disruption of family interaction | 2.23 (1.04) | 1.67 (.74) |
| Effect on physical health of others | .47 (.74) | .23 (.34) |
| Effect on mental health of others | 1.13 (.82) | .56 (.41) |
| Total objective burden | 27.80 (5.61) | 1.15 (.23) |
| Subjective burden | 1.43 (.67) | 1.83 (.53) |
| Subjective burden | | |
| No burden | 3 (10%) | |
| Moderate burden | 11 (36.7%) | |
| Severe burden | 16 (53.3%) | |
| FBI total burden score (> 12) | 30 (100%) | |
| <i>Caregiver Strain Index (CSI)</i> | | |
| Inconvenience | 4.73 (1.31) | .73 (.19) |
| Adjustment | 2.1 (1.09) | .70 (.36) |
| Work adjustment | .53 (.63) | .26 (.31) |
| Upsetting | .93 (.25) | .93 (.25) |
| Total CSI Score | 8.80 (2.76) | 1.80 (.41) |
| Total CSI score (≥ 7) | 24 (80%) | |
| <i>Multidimensional aspect of perceived social support (MPSS)</i> | | |
| Friends social support | 17.60 (4.90) | 4.43 (1.52) |
| Family social support | 19.47 (6.88) | 4.87 (1.72) |
| Significant others social support | 17.73 (6.07) | 4.43 (1.52) |
| Total MPSS score | 54.80 (14.13) | 4.57 (1.17) |
| Level of perceived support | | |
| Low acuity (12–48) | 15 (50%) | |
| Moderate acuity (49–68) | 6 (20%) | |
| High acuity (69–84) | 9 (30%) | |
| <i>Cognitive and behaviour avoidance scale (CBAS)</i> | | |
| Cognitive social avoidance | 15.23 (4.00) | 2.18 (.57) |
| Cognitive non-social avoidance | 20.40 (6.77) | 2.04 (.68) |
| Behaviour social avoidance | 16.03 (4.57) | 2.00 (.56) |
| Behaviour non-social avoidance | 13.20 (3.34) | 2.20 (.56) |
| Non-social avoidance total | 33.60 (9.32) | 2.10 (.58) |
| Social avoidance total | 31.27 (8.00) | 2.08 (.53) |
| Total CBAS score | 64.86 (16.70) | 2.09 (.54) |
| <i>Ways of coping checklist (WCC)</i> | | |
| Escaping avoidance coping | 14.00 (4.66) | 1.75 (.58) |
| Distancing coping | 13.53 (3.27) | 2.25 (.54) |
| Confrontative coping | 12.17 (2.71) | 2.02 (.45) |
| Self-controlling coping | 18.20 (4.75) | 2.60 (.67) |
| Seeking social support | 15.93 (3.65) | 2.66 (.61) |
| Acceptability responsibility coping | 8.23 (3.53) | 2.06 (.88) |
| Planful problem solving coping | 15.90 (4.31) | 2.65 (.72) |
| Positive appraisal coping | 15.23 (4.75) | 2.18 (.68) |
| <i>General Health Questionnaire-12</i> | | |
| Total score | 3.27 (1.76) | .27 (.15) |
| ≥ 2 | 24 (80%) | |

^aWeighted scores were calculated by dividing the total score for the particular domain by number of items included in that domain

Table 3 Association of burden and perceived social support

| | Friends social support | Significant others social support | Family social support | Total MPSS |
|--|------------------------|-----------------------------------|-----------------------|-------------------|
| <i>Family burden interview schedule</i> | | | | |
| Financial burden | – .39* (.04) | – .39* (.03) | – .59*** (.001) | – .59*** (.001) |
| Disruption of routine family activities | – .40* (.03) | | – .661*** (< .001) | – .571*** (.001) |
| Disruption of family interaction | – .44* (.02) | | – .70*** (< .001) | – .61*** (< .001) |
| Effect on physical health of others [#] | – .47** (.009) | | – .50** (.005) | – .51** (.004) |
| Effect on mental health of others | – .38* (.04) | – .48** (.01) | – .42* (.02) | – .54** (.002) |
| Objective burden | – .52** (.003) | – .47** (.01) | – .77*** (< .001) | – .76*** (< .001) |
| <i>Caregiver Strain Index</i> | | | | |
| Inconvenience | – .47** (.01) | | – .59*** (.001) | – .58*** (.001) |
| Adaptation | | | – .43* (.02) | |
| Total score of CSI | | | – .63*** (< .001) | – .55** (.002) |

[#]Spearman rank correlation coefficient

When the correlations of burden with social support were evaluated, as depicted in Table 3, low social support was associated with higher burden in all domains of FBI except disruption in family leisure and subjective burden.

Poor social support was also associated with significantly higher “inconvenience” and total CSI score.

Association of Burden with Coping

Higher use of avoidance coping (both social and non-social) 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 behaviour social avoidance component of CBAS. In terms of CSI, higher use of avoidance coping (both social and non-social) was associated with significantly higher burden as assessed by CSI total score (see Table 4).

When the relationship of burden was evaluated with WCC, higher use of ‘distancing’ was associated with higher burden in all the domains of FBI (except disruption of routine family activities) and CSI; higher use of ‘escaping’ was associated with higher disruption of routine family activities and total objective burden in the domains of FBI; and in ‘inconvenience’ domain of CSI. Lower use of positive appraisal and acceptability–responsibility as coping mechanisms were associated with higher total objective burden.

GHQ total score correlated positively with all domains of FBI except effect on physical and mental health of others; while it had positive correlation with adaptation and total CSI score.

Discussion

Caregivers of patients with cancer are considered as the “hidden sufferers” when the whole cancer experience is taken into consideration. Family caregivers are more vulnerable because they not only have to face the patient’s emotional reaction, but also have to deal with their own emotional reactions [32]. Although some of the studies have evaluated the caregiver burden among the caregivers of patients with ALL [33–35], very few studies have evaluated caregiver burden in AML. Further these studies have focused on only one or two correlates in the form of social support [36], coping [34, 35] and psychological morbidity [33], 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 AML. Present study attempted to fill this void.

This study utilized a framework derived from the ‘stress-appraisal-coping’ of caregiving [37, 38]. In the present study, 2 scales (FBI & CSI) were used simultaneously for assessment of burden to broaden the assessment. In the present study the mean FBI objective burden score was 27.8 and mean subjective burden score was 1.83 with 53.3% of the caregivers reporting severe burden. Very few studies have used FBI to evaluate the caregiver burden among caregivers of patients with various physical illnesses. Hence, it is difficult to compare the findings of the present study with the existing literature on caregiver burden among patients with AML with other physical illnesses. However, FBI has been quite frequently used among caregivers of patients with severe mental disorders [39–41]. When we compare this findings with that reported for caregivers of patients with schizophrenia [39], bipolar

Table 4 Association between coping and GHQ with caregiver burden among caregivers

| | Family burden interview schedule | | | | Caregiver strain Index | | | Total score of CSI | | |
|--------------------------------|----------------------------------|---|----------------------------------|-------------------------------------|-----------------------------------|-------------------|----------------------------|--------------------|---------------|---------------|
| | Financial burden | Disruption of routine family activities | Disruption of family interaction | Effect on physical health of others | Effect on mental health of others | Subjective burden | FBI total objective burden | | Inconvenience | Adaptation |
| <i>CBAS</i> | | | | | | | | | | |
| Cognitive social avoidance | .47** (.01) | .47** (.009) | | | | | .48** (.007) | | | |
| Cognitive non-social avoidance | .46** (.01) | .39* (.03) | | | | | .42* (.02) | | | |
| Behaviour social avoidance | .62*** (<.001) | | .37* (.05) | .40* (.03) | | .37* (.04) | .56*** (.001) | .45** (.01) | .49** (.006) | .49** (.006) |
| Behaviour non-social avoidance | .66*** (<.001) | .56** (.001) | .38* (.04) | .39* (.04) | | | .66*** (<.001) | .55*** (.002) | .52*** (.003) | .58*** (.001) |
| Non-social avoidance total | .57** (.001) | .48** (.007) | .38* (.04) | | | | .54** (.002) | .44* (.02) | .42* (.02) | .45** (.01) |
| Social avoidance total | .59*** (.001) | .43* (.02) | .39* (.04) | | | | .56*** (.001) | .43* (.02) | .41* (.02) | .45** (.01) |
| Total of avoidance | .60*** (<.001) | .48** (.01) | .40* (.03) | | | | .57*** (.001) | .45** (.01) | .43** (.01) | .47*** (.009) |
| <i>WCC</i> | | | | | | | | | | |
| Escaping | | .47** (.009) | | | | | | | | |
| Distancing | .37* (.05) | | .37* (.05) | .46** (.01) | .44* (.02) | | .38* (.04) | .43* (.02) | | |
| Confrontative | | .38* (.04) | | | | | .48** (.008) | .52*** (.003) | .41* (.03) | .53*** (.003) |
| Self controlling | | -.51** (.004) | | | | | | | | |
| Acceptability—responsibility | | -.53** (.003) | | | | | | | | |
| Planful | | -.42* (.02) | | | | | | | | |
| problem solving | | | | | | | | | | |
| Positive appraisal | | -.46* (.01) | | | | | | | | |
| <i>GHQ</i> | | | | | | | | | | |
| GHQ total score | .54** (.003) | .55** (.002) | .40* (.03) | | | .62*** (<.001) | .55** (.002) | .40* (.03) | .41* (.03) | .41* (.03) |

disorder [40], obsessive compulsive disorder [42], non-Hodgkin's lymphoma [43], acute lymphoblastic leukemia [44] and other chronic physical illness [45], it can be said that the caregiver burden experienced by the caregivers of AML is significantly higher than that reported by the caregivers of various severe mental disorders. The higher level of burden among the caregivers of AML was seen in all the sub domains of objective burden and also in subjective burden, when compared to patients with severe mental disorder [39–45]. Among the various components of objective burden, highest score was noted for the domain on family leisure, followed by disruption of family interaction, disruption of routine family activities and financial burden. Studies from West, which have evaluated the cost of management of AML, also suggest that, financial issues are one of the major reason for not taking treatment [19]. Studies which have evaluated caregiver burden by using CSI also suggest that the caregiver burden experienced by the caregivers of patients with AML is more than other illnesses like dementia [46], schizophrenia [47, 48] and stroke [49].

The high level of caregiver burden experienced by the caregivers of AML compared to other physical illnesses and psychiatric disorders can be understood by the nature of AML as an illness, which is associated with high mortality rates. Accordingly, it can be said that the caregivers of patients with AML 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.

Caregivers of female patients scored higher in the domain of “overwhelmed” and married caregivers reported more disruption of family leisure than unmarried. In a developing country like India, women plays multiple roles, take part in both household chores and outdoor activities to manage their home. So, female caregivers face more challenges while caregiving for AML patients, as treatment is more time consuming. Also, married caregivers scored higher in the domain of inconvenience, overwhelmed and total CSI score than unmarried caregivers, can be explained due to same reason. Those who were from middle or low socio-economic status reported more financial burden on FBI which can be explained when we see overall treatment and security costs of AML.

In the present study, it emerged that poor social support was associated with significantly higher burden in all the domains of FBI except for ‘disruption of family leisure’ and objective burden. 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 [50].

Accordingly, it can be said that any effort to improve the social support of caregivers of patients with AML 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 acceptability–responsibility 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 [44]. The present study also supports the hypothesis that lower reliance on avoidant coping would be associated with better caregiver adjustment. Accordingly, it can be said that the clinicians dealing with the caregivers of patients with AML 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, disruption of routine family activities, disruption of family interaction and total objective burden 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 [13, 14]. Accordingly, it can be said that reducing the caregiver burden can lead to reduction in the psychological morbidity among the caregivers of patients with AML.

The present study has certain limitations. The study involved cross-sectional assessment of a small sample of caregivers. Future studies should try to overcome the limitations of the present study.

Conclusion

To conclude, this study suggests that caregivers of patients with AML 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, presence of higher burden is associated with higher psychological morbidity. So, 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.

Compliance with Ethical Standards

Conflict of interest None. Authors have full control of all primary data and the journal can review the data if requested.

Ethical Approval Approval was sought from the Ethics Committee of the Institute, where this study was conducted. This study involved human participants and all were recruited after obtaining written informed consent. There are no potential conflict of interests of any of the authors, with respect to the subject evaluated in this manuscript.

References

- National Cancer Institute—Surveillance, Epidemiology, and End Results Program [Internet]. Bethesda: The Surveillance, Epidemiology, and End Results (SEER) Program of the National Cancer Institute (NCI); Last updated Sep 12, 2016; cited on 23/01/2017. https://seer.cancer.gov/csr/1975_2013/browse_csr.php?sectionSEL=13&pageSEL=sect_13_table.16.html. Accessed 23 Jan 2017
- Bevans MF, Sternberg EM (2012) Caregiving burden, stress, and health effects among family caregivers of adult cancer patients. *JAMA* 307:398–403
- Song JI, Shin DW, Choi JY, Kang J, Baik YJ, Mo H et al (2011) Quality of life and mental health in family caregivers of patients with terminal cancer. *Support Care Cancer* 19:1519–1526
- Given BA, Given CW, Kozachik S (2001) Family support in advanced cancer. *CA Cancer J Clin* 51:213–231
- Yun YH, Rhee YS, Kang IO, Lee JS, Bang SM, Lee WS et al (2005) Economic burdens and quality of life of family caregivers of cancer patients. *Oncology* 68:107–114
- Ferrell B, Hanson J, Grant M (2013) An overview and evaluation of the oncology family caregiver project: improving quality of life and quality of care for oncology family caregivers. *Psychooncology* 22:1645–1652
- Johnson FL, Rudolph LA, Hartman JR (1979) Helping the family cope with childhood cancer. *Psychosomatics* 20:241–251
- Lansky SB, Black JL, Cairns NU (1983) Childhood cancer. Medical costs. *Cancer* 52:762–766
- Pinquart M, Sörensen S (2003) Differences between caregivers and noncaregivers in psychological health and physical health: a meta-analysis. *Psychol Aging* 18:250–267
- Bond JT, Galinsky E, Swanberg JE (1998) The 1997 national study of the changing workforce. Families and Work Institute, New York
- Neal M, Wagner LD (2001) Working caregivers: issues, challenges and opportunities for the aging network. Administration on Aging, Washington, DC
- Altman BM, Cooper PF, Cunningham PJ (1999) The case of disability in the family: impact on health care utilization and expenditures for nondisabled members. *Milbank Q* 77:39–75
- Tamayo GJ, Broxson A, Munsell M, Cohen MZ (2010) Caring for the caregiver. *Oncol Nurs Forum* 37:E50–E57
- Tremolada M, Bonichini S, Aloisio D, Schiavo S, Carli M, Pillon M (2013) Post-traumatic stress symptoms among mothers of children with leukemia undergoing treatment: a longitudinal study. *Psycho-oncology* 22:1266–1272
- Malpert AV, Kimberg C, Luxton J, Mullins LL, Pui CH, Hudson MM et al (2015) Emotional distress in parents of long-term survivors of childhood acute lymphoblastic leukemia. *Psychooncology* 24:1116–1123
- Ross JW, Klar H (1982) Mental health practice in a physical health setting. *Soc Casework* 63:147–154
- Han HR, Cho EJ, Kim D, Kim J (2009) The report of coping strategies and psychosocial adjustment in Korean mothers of children with cancer. *Psychooncology* 18:956–964
- Philip C, George B, Ganapule A, Korula A, Jain P, Alex AA et al (2015) Acute myeloid leukaemia: challenges and real world data from India. *Br J Haematol* 170:110–117
- Kusumgar S, Johnson K, Belford M, Desai A, He J (2015) Patient-relevant experiences and impacts of acute myeloid leukemia: evidence from online social networks-based qualitative research. *Blood* 126:4523
- Brackley M (1994) The plight of American family caregivers: implications for nursing. *Pers Psychiatry Care* 30:14–20
- Pai S, Kapur RL (1981) The burden on the family of a psychiatric patient: development of an assessment scale. *Br J Psychiatry* 138:332–335
- Sullivan MT (2002) Caregiver strain index. *J Gerontol Nurs* 28:4–5
- Robinson B (1983) Validation of a caregiver Strain Index. *J Gerontol* 38:344–348
- Zimet GD, Powell SS, Farley GK, Werkman S, Berkoff KA (1990) Psychometric characteristics of the Multidimensional Scale of Perceived Social Support. *J Pers Assess* 55:610–617
- Ottenbreit ND, Dobson KS (2004) Avoidance and depression: the construction of the cognitive-behavioral avoidance scale. *Behav Res Ther* 42:293–313
- Folkman S, Lazarus RS (1980) An analysis of coping in a middle-aged community sample. *J Health Soc Behav* 21:219–239
- Folkman S, Lazarus RS (1985) If it changes it must be a process: study of emotion and coping during three stages of a college examination. *J Pers Soc Psychol* 48:150–170
- Gautam S, Nijhawan M, Kamal P (1987) Standardisation of hindi version of Goldberg's General Health Questionnaire. *Indian J Psychiatry* 29:63–66
- Goldberg DP, Blackwell B (1970) Psychiatric illness in general practice. A detailed study using a new method of case identification. *Br Med J* 1:439–443
- Katz S, Down TD, Cash HR, Grotz RC (1970) Progress in the development of the index of ADL. *The Gerontologist* 10:20–30
- Katz S, Ford AB, Moskowitz RW, Jackson BA, Jaffe MW (1963) Studies of illness in the aged: the index of ADL: a standardized measure of biological and psychosocial function. *JAMA* 185:914–919
- Rabow MW, Hauser JM, Adams J (2004) Supporting family caregivers at the end of life. *JAMA* 291:483–491
- Sharan P, Mehta M, Chaudhry VP (1999) Psychiatric disorders among parents of children suffering from acute lymphoblastic leukemia. *Pediatr Hematol Oncol* 16:43–47
- McGrath P (2000) Confronting icarus: a psycho-social perspective on haematological malignancies. Ashgate Publishers, Aldershot, pp 26–93
- McGrath P (1999) New directions in leukaemia research: a focus on psychosocial issues from a consumers' perspective. *Aust Soc Work* 52:39–45
- Baxandall S, Reddy P (1993) The courage to care: the impact of cancer on the family. David Lovell, Melbourne
- Lazarus RS, Folkman S (1984) Stress, appraisal, and coping. Springer, New York
- Lazarus RS (1966) Psychological stress and the coping process. McGraw-Hill, New York
- Pradyumna S (2014) Coping strategies and their correlates in caregivers of patients with schizophrenia: an exploratory study. M.D. thesis (Psychiatry), PGIMER, Chandigarh
- Sharma N (2014) The relationship of gender and burden among caregivers of patients with chronic mental illnesses. M.D. thesis (Psychiatry), PGIMER, Chandigarh

41. Gupta A, Sharma R (2013) Burden and coping of caregivers of physical and mental illnesses. *Delhi Psychiatry J* 16:367–374
42. Grover S, Dutt A (2011) Perceived burden and quality of life of caregivers in obsessive–compulsive disorder. *Psychiatry Clin Neurosci* 65:416–442
43. Kulhara P, Marwaha R, Das K, Aga VM et al (1998) Burden of care in parents of children suffering from haematological malignancies. *Indian J Psychiatry* 40:13–20
44. Kumari R (2015) Burden of caregiving and its correlates in the patients of acute lymphoblastic leukemia. M.D. thesis (Psychiatry), PGIMER, Chandigarh
45. Khanna AK, Prabhakaran A, Patel P, Ganjiwale JD, Nimbalkar SM (2015) Social, psychological and financial burden on caregivers of children with chronic illness: a cross-sectional study. *Indian J Pediatr* 82:1006–1011
46. Heinz MS (2010) Dementia caregiving characteristics, elder impairment, and caregiver strain and burden. Graduate theses and dissertations paper 11283, Iowa State University
47. Elmahdi M, Kamel F, Esmael A, Lotfi M, Kamel A, Elhosini A (2011) Burden of care on female caregivers and its relation to psychiatric morbidity. *Middle East Curr Psychiatry* 18:65–71
48. Amira A, Fouad MMF, Masry EN (2013) Psychosocial burden among caregivers of patients with Schizophrenia in Egypt. *ZUMJ* 19:611–618
49. Hung JW, Huang YC, Chen JH (2012) Factors associated with strain in informal caregivers of stroke patients. *Chang Gung Med J* 35:392–401
50. Nijboer C, Tempelaar R, Sanderman R, Triemstra M, Spruijt R (1998) Cancer and caregiving: the impact on the caregiver's health. *Psycho-oncology* 7:3–13

Publisher's Note Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.