Correlates of Positive Aspects of Caregiving Among Family Caregivers of Patients with Acute Myeloblastic Leukaemia

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Abstract To evaluate the positive aspects of caregiving and its sociodemographic and clinical correlates in family caregivers of patients with Acute Myeloblastic Leukaemia (AML). A total of 30 caregivers of the patients with AML were evaluated on the Scale for Positive Aspects of Caregiving Experience (SPACE), Family Burden Interview (FBI) and Schedule and Caregiver Strain Index (CSI). On the SPACE, the mean score was highest for the domain of motivation for the caregiving role, followed by the domain of ‘caregiving personal gains’, ‘caregiver satisfaction’ and least score was seen in the domain of ‘self-esteem and social aspect of caring’. All the SPACE domains were negatively correlated with financial burden, disruption of routine family activities, disruption of family interaction, physical health and subjective burden domains of FBI. Effect on physical health of others domain of FBI correlated negatively with all domains of SPACE except ‘self esteem and social aspect of caregiving’. FBI total objective burden was negatively correlated with motivation for caregiving role, caregiver satisfaction and total SPACE score. All SPACE domains were negatively correlated with adaptation and inconvenience domains and total CSI score. Lower level of positive caregiving experience is reported by caregivers who experience high level of caregiver burden.

Keywords Caregivers · Acute myeloblastic leukaemia · Cancer · Burden

Introduction

Acute myeloid leukaemia (AML) is associated with significant caregiving needs. In general caregiving is understood as caregiver burden, which basically attributes all the problems in the life of caregiver to the patient’s illness and resultantly reflects negative caregiving experience. Over the years burden or negative experience of caregiving has been the focus of research, however, in recent times studies have also reported positive aspects of being in the caregiver role [1]. Positive aspects of caregiving (PAC) have been recognised as reward, meaning, commitment, purpose in life, love, affection and joyful events [2]. PAC among caregivers are often associated with a sense of pride, self-worth [3] or higher self-esteem [4]. In more recent studies involving caregivers of different illnesses, positive aspects of caregiving were more explicitly understood as uplifts [1], gratification [3], appraisal, satisfaction [1.5], mastery and ideology [6], motivation for caregiving [5]. Some of the studies suggest that at times illness binds the families together and caregivers often report that the time they spend with their ill relative as quality time and caregiving is described as meaningful, purposeful, and satisfying. At the same time, the process of caregiving has also been described as if riding an emotional roller coaster in which caregivers have to struggle with their own feelings [7]. However, the data is inconclusive in terms of the effect of positive and negative caregiving on the caregivers. Understanding PAC and recognising its predictors can provide information how PAC can be enhanced among the caregivers [8].

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In resource poor countries like India, where little help [9] and guidance [10] is offered to caregivers, they impart vital service to society, despite going through the struggle to fulfil their caregiver roles. Little information is available in terms of PAC among caregivers of patients with AML. In this background this study aimed to evaluate the caregiver burden and PAC among the caregivers of adolescent and adult patients of AML.

Materials and Methods

This study was conducted in a tertiary care hospital. For inclusion into the study, the patients with AML were required to be aged more than 12 years. The inclusion criteria for the caregivers required them to be aged more than 18 years and proficient to read Hindi and/or English. To be considered as a caregiver, participants must have been living with the patient since the time of diagnosis and involved in taking care of the patient, i.e., attending to the daily needs, supervision of medications, bringing the patient to the hospital, staying with the patient during the inpatient stay, and liaising with the treating team. Caregivers were also required to be free from any diagnosed mental disorder and not involved concurrently in the care of any other ill relative.

The positive aspect of caregiving was evaluated by Scale of Positive Aspects of Caregiving Experience (SPACE) [11]. Negative consequences of caregiving among the caregivers was evaluated by Family Burden Interview Schedule [10] (FBI) and Caregiver Strain Index (CSI) [12, 13].

Scale of Positive Aspects of Caregiving Experience [11] has 44 items, with 5 anchor points (0–4) to rate the various positive aspects of being in the caregiver role. Items of the scale are grouped into 4 domains: Caregiver personal gains, motivation for caregiving role, caregiver satisfaction, self-esteem and social aspects of caregiving. As the 4 domains have unequal number of items, mean weighted score is calculated for each domain by dividing the total domain score with total number of items in the domain. The internal consistency ($\alpha = 0.92$), split half reliability (Spearman Brown coefficient = 0.83), test–retest reliability and cross-language reliability of the scale has also been reported to be high [14]. This scale has been used to study positive caregiving experience among patients with mental illnesses like schizophrenia, bipolar disorder, obsessive compulsive disorder and diabetes mellitus in the past.

Family Burden Interview Schedule, which is a semi-structured interview schedule, comprises of 24 items, which are organized into six areas of objective (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) burden and one item evaluate the subject burden [10]. All the items of the scale are rated as: 0 indicating no, 1 indicating moderate and 2 indicating severe burden. Additionally a global rating of the family burden is done by the clinician. Total score of more than 12 for the objective burden is considered to be an indicator of severe burden [10].

CSI is a self administered instrument comprising of 13-questions which assess the strain related to care provision. The items are divided into domains of inconvenience, emotional adjustment, upsetting and work adjustment. Positive responses to ≥ 7 items indicate a higher level of caregiver strain [12, 13].

Katz Index of Independence in Activities of Daily Living (ADL) was used to evaluate the ability of the patients to perform activities of daily living independently in the domains of bathing, toileting, continence, transferring, dressing, and feeding [15]. All the 6 functions as assessed by the scale are rated as yes/no, with yes given a score of 1. A total score of 6 suggests full function, score of 4 suggests moderate impairment, and a score of 2 or less indicates severe functional impairment.

For this study, patients with AML attending the Haematological services of the hospital were approached during their routine visit to the hospital. They were explained about the study and consenting patients and caregivers were recruited. All the assessments were carried out over one session by a trainee psychiatrist.

SPSS-14 version was used to carry out the analysis. Descriptive analysis of data involved calculation of mean, standard deviation, range, frequencies and percentages. Associations between positive aspects of caregiving with other variables were evaluated by using Pearson correlation coefficient and Spearman's rank correlation. Comparisons were carried out by using Chi square test, Fisher exact test, *t* test and Mann–Whitney U test.

Results

Socio-demographic Profile of the Study Sample

The age of patients varied from 12 to 66 years with a mean of 40.67 years (SD 14.25) and a median of 41 years. Females (56.7%) outnumbered males and those from urban locality (56.7%) outnumbered patients from rural background. Most of the patients were married (80%), educated beyond matriculation (66.7%), and belonged to the middle socioeconomic class (76.7%). Patients received formal education for 12.33 years (SD 4.80) and the mean monthly family income of patients was Rupees 54,650 (SD

43,965.73). Less than half of the patients (43.3%) of patients were on paid employment.

Age of the caregivers was 42.37 years (SD 11.25). More than half (56.7%) of the caregivers were male and majority of them were married (86.7%). Caregivers spent 14.5 h (SD 2.57; range 7–18) in meeting the caregiving needs.

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. Three-fifth of the patients had restricted activity of daily living at the time of the assessment. The mean KATZ index score was 4.83 (SD 1.51), indicating severe restriction in functionality.

Caregiving: Impact on the Caregivers

On SPACE, mean weighted score was highest for the domain of “Motivation for the caregiving role”, followed by the domain of “Caregiving personal gains”, “Caregiver satisfaction” and least for the domain of “self-esteem and social aspect of caring”. The mean total score of the 4 domains (which include 44 items of the scale) was 87.36 (SD 27.96).

On FBI, more than half of the caregivers reported severe subjective burden (53.3%) and another one-third reported moderate level of objective burden (36.7%). In terms of various domains of objective domain, domain of ‘disruption of routine family activities’ was the most affected and ‘effect on physical health of others’ was the least affected. When the cut-off of 12 was taken as an indicator of severe objective burden, all caregivers reported severe objective burden. On CSI, more than three-fourth (80%) of the caregivers reported significant caregiver strain. In terms of various domains of CSI, maximum strain was reported in the domain of “upsetting” and the least strain was reported for the domain of “work adjustment”(Table 1).

Association of Burden with Positive Aspects of Caregiving

As evident from Table 2, in general various domains of SPACE correlated negatively with FBI and CSI. Significantly lower ‘caregiver’s personal gain’ and ‘self-esteem and social aspect of caregiving’ were associated with higher scores in the domains of financial burden, disruption of routine family activities, and disruption of family interaction, effect on physical health of others. ‘Motivation for the caregiving role’, ‘caregiver satisfaction’ and ‘overall positive caregiving experience’ as assessed by SPACE was also significantly low among those caregivers who reported higher scores in the domains ‘disruption of routine family activities’ and ‘disruption of family

interaction’ on FBI and ‘inconvenience’ and those with higher CSI score. Upsetting domain of CSI correlated negatively with the ‘caregiver satisfaction’ and ‘self-esteem and social aspects of caregiving’ domains of SPACE.

Subjective and total objective burden had negative correlation with all the domains of SPACE. Total CSI score also correlated negatively with all domains of SPACE.

Discussion

Caregiving for sick relatives is often challenging. Caregivers may experience both negative and positive consequences of the whole caregiving process. Most of the available literature on caregiving associated with various cancers is limited to negative caregiving experience. These studies have reported negative caregiving experience in terms of psychological distress, burnout, poor health, depression/depressive symptoms, anxiety, caregiver burden, and unmet social needs [16, 17]. Occasional study has evaluated the PAC among caregivers of patients with cancer. In one of the study, the caregivers described that experience of caregiving was associated with a personal feeling of being needed. Taking care of their ill relatives added meaning to their lives, helped them to learn new skills, and strengthened their relationship with the care-recipient and with other family members [18]. Another study which evaluated the benefits of being a caregivers among patients with cancer, identified acceptance, empathy, appreciation, family closeness, a positive self-view, life satisfaction and a reprioritization of values as 6 important domains of benefit [19]. This study also showed that those caregivers who reported becoming more empathetic toward others and were able to reprioritizing their values reported less of depression [19].

Overall, the PAC among cancer patients has been relatively less studied and has not been explored at all among the caregivers of patients with AML. The lack of acknowledgment of the PAC seriously influences the perceptions about the whole caregiving experience, which creates a barrier in enhancing caregiver adaptation to a severe illness. Accordingly, the present study was attempted to explore this uncharted territory.

Positive aspect of caregiving was assessed by using SPACE, which is an instrument validated among caregivers of patients with severe mental disorders in the Indian setting [11]. Among the various domains of SPACE, mean weighted score was highest for the domain of “motivation for the caregiving role”, followed by the domain of “caregiving personal gains”, “caregiver satisfaction” and least for the domain of “self-esteem and social aspect of caring”. This hierarchy of positive aspect of caregiving is slightly different from that reported for other chronic

Table 1 Caregiver burden and positive aspects of caregiving

Variable	Weighted mean scores ^a (SD)
<i>Scale of positive aspects of caregiving experience (SPACE)</i>	
Caregiving personal gains	1.83 (0.61)
Motivation for the caregiving role	2.32 (0.79)
Caregiver satisfaction	2.70 (0.64)
Self-esteem and social aspect of caring	1.61 (0.71)
Total SPACE score	1.99 (0.64)
<i>Family burden interview schedule (FBI)</i>	
Financial burden	1.25 (0.51)
Disruption of routine family activities	1.27 (0.23)
Disruption of family leisure	1.89 (0.16)
Disruption of family interaction	1.67 (0.74)
Effect on physical health of others	0.23 (0.34)
Effect on mental health of others	0.56 (0.41)
Total objective burden	1.15 (0.23)
Subjective burden	1.83 (0.53)
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	0.73 (0.19)
Emotional adjustment	0.70 (0.36)
Upsetting	0.26 (0.31)
Work adjustment	0.93 (0.25)
Total CSI score	1.80 (0.41)
Total CSI score (≥ 7)	24 (80%)

^aThe total score for the particular domain was divided by the number of items included in that domain to calculate the weighted scores

physical and psychiatric disorders. In a study evaluating caregivers of patients with type-1 diabetes mellitus, highest score was noted for the domain of “self-esteem and social aspect of caring” followed by the domains of “caregiver’s personal gains,” “caregiver satisfaction” and the least for the domain of “motivation for the caregiving role” [20]. The findings of this study are more akin to that reported for caregivers of patients with schizophrenia [5], bipolar disorder [21] and dementia [22], who also had highest mean scores for the domain of “motivation for the caregiving role,” followed by ‘caregiver satisfaction’, ‘caregiver personal gains’ and the least score for the domain of ‘self-esteem and social aspect of caring’. Further, the scores obtained by the caregivers of AML were also comparable to that reported by caregivers of patients with schizophrenia, bipolar disorder and dementia. The similarity between the positive aspect of caregiving among caregivers of the AML and severe mental disorder like schizophrenia can be understood in terms of nature of these illnesses. Both these

illnesses are associated with a sense of loss among the caregivers and the patients have to depend on the caregivers for most of their needs due to the associated disability. AML is further associated with a threat of impending mortality. In contrast to AML, diabetes mellitus is not that disabling and is not associated with a threat of death. Accordingly, it can be said that in terms of positive aspect of caregiving, caregivers of AML report similar experience as reported by the caregivers of patients with severe mental disorders and dementia.

In terms of relationship of positive aspect of caregiving with caregiver burden and caregiver strain index, in general higher negative caregiving was associated with lower level of positive caregiving experience. There is lack of consensus in terms of association of positive and negative aspect of caregiving among patients with cancer. Some of the studies suggest that high caregiver satisfaction has been reported despite high rates of distress in caregivers of cancer patients [23, 24]. In terms of ‘self-esteem and social

Table 2 Association of burden and positive aspects of caregiving

	Caregiver personal gains	Motivation for the caregiving role	Caregiving satisfaction	Self-esteem and social aspect of caregiving	Total SPACE score
<i>Family burden interview schedule</i>					
Financial burden	– .71*** ($< .001$)	– .78*** ($< .001$)	– .74*** ($< .001$)	– .72*** ($< .001$)	– .82*** ($< .001$)
Disruption of routine family activities	– .58** (.001)	– .48** (.008)	– .36* (.05)	– .58** (.001)	– .55** (.002)
Disruption of family interaction	– .64*** ($< .001$)	– .56** (.001)	– .62*** ($< .001$)	– .56** (.001)	– .66*** ($< .001$)
Effect on physical health of others ^a	– .39* (.04)	– .44* (.02)	– .45* (.01)	– .36* (.05)	– .47* (.01)
FBI total objective burden		– .47* (.01)	– .42* (.02)		– .38* (.04)
Subjective burden	– .78*** ($< .001$)	– .79*** ($< .001$)	– .73*** ($< .001$)	– .77*** ($< .001$)	– .85*** ($< .001$)
<i>Caregiver strain index</i>					
Inconvenience	– .60*** ($< .001$)	– .64*** ($< .001$)	– .71*** ($< .001$)	– .53** (.003)	– .68*** ($< .001$)
Adaptation	– .40* (.03)	– .59** (.001)	– .55** (.002)		– .52** (.004)
Upsetting ^a			– .44* (.02)	– .46* (.01)	– .42* (.02)
Total score of CSI	– .59*** ($< .001$)	– .69*** ($< .001$)	– .76*** ($< .001$)	– .53*** ($< .001$)	– .71*** ($< .001$)

^aSpearman correlation value for calculation of physical health domain of FBI schedule and ‘upsetting domain of CSI, Pearson correlation for other domains

* $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$

aspect of caregiving’ available literature suggests that self-esteem of caregivers of cancer patients is associated with conditions of life, especially financial [25]. Some of the differences can be understood due to the differences in the assessment instruments. Accordingly, it can be said that the findings of the present study must be considered as preliminary and must be replicated in future studies.

There are certain limitations of this study. The study involved cross-sectional assessment of a small sample of caregivers. Future studies must attempt to overcome the limitations of the present study.

To conclude, this investigation suggests that caregivers of patients with AML experience both positive and negative consequences of caring for their ill relatives. Further the positive aspect of caregiving is negatively related to the negative caregiving experience. Hence, any effort to reduce the negative impact of caregiving on the caregivers can possibly improve the overall positive caregiving experience of caregivers of AML.

Compliance with Ethical Standards

Ethical Approval The study was approved by the Ethics Committee of the Institute and declaration of Helsinki. All the patients and caregivers provided written informed consent prior to induction into the study. The study was not funded by any funding agency.

Conflict of interest All authors declare that they have no conflict of interest.

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