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ASSOCIATION BETWEEN CARE BURDEN AND QUALITY OF LIFE OF FAMILY CAREGIVERS OF BONE MARROW TRANSPLANT PATIENTS AT ARMED FORCE BONE MARROW TRANSPLANT CENTER, RAWALPINDI

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ABSTRACT

Background: Bone marrow transplantation (BMT) requires a significant amount of support from family members, which can impact their physical, psychological, social and emotional health.

Objective: To evaluate caregiver burden, quality of life (QoL) and see its correlation among family caregivers of bone marrow transplant (BMT) patients at Armed Forces Bone Marrow Transplant Center (AFBTC) Rawalpindi.

Methodology: Using consecutive sampling, a cross sectional correlational study was conducted with 202 family caregivers between May and July of 2025. The participants were the adults who care for the post-transplant patients for not less than one month. The Zarit Burden Interview (ZBI) and Quality of Life – Family Version (QOL-FV) were completed as measures to capture data. Descriptive statistics, Pearson's correlation, ANOVA and linear regression were used, and $p<0.05$ was accepted as significant.

Results: Among 202 caregivers, 110 (54.5%) were female and 92 (45.5%) were male; parents constituted 45 (22.3%) and siblings 42 (20.8%). Burden-related concerns were reported as sometimes by 67 (33.2%), rarely by 53 (26.2%), and frequently by 46 (22.8%) participants. Regarding QoL, 77 (38.0%) caregivers had moderate QoL, 65 (32.0%) good QoL, 40 (20.0%) poor QoL, 16 (8.0%) excellent QoL, and 12 (6.0%) very poor QoL. Caregiver burden showed a strong negative correlation with QoL ($r=-0.798$, $p<0.001$). Regression demonstrated that burden significantly predicted poorer QoL ($\beta=-0.798$, $p<0.001$), explaining 63.7% of its variance.

Conclusion: Regular evaluation of the caregiver burden and provision of education, social support, and respite services are important in BMT care, as this is strongly correlated with poorer QoL.

KEYWORDS: Bone marrow transplantation; family caregivers; caregiver burden; quality of life; Zarit Burden Interview; QOL-FV.

INTRODUCTION

Transplantation of bone marrow (also known as hematopoietic stem cell transplantation) is a critical therapy for patients with hematological malignancies or other severe blood diseases [1,2]. While transplantation can offer potential for long term disease control or cure, the treatment can be complex and beyond hospitalisation [3]. During the recovery process, patients may need ongoing monitoring and support for recovery, including psychological support, which can lead to prolonged immunosuppression, treatment-related complications, infections, fatigue, nutritional issues, and psychological distress [4]. Thus, often family members host a significant amount of physical, emotional, social, and practical support that comes with transplantation [5].

Family caregivers are key players in the care that is provided to patients throughout the transplantation experience [6]. They can be involved in a variety of tasks such as helping to administer medicines, maintaining infection control, checking for symptoms, taking patients to medical visits, overseeing dietary needs, and offering emotional support [7]. This can be especially challenging if your patients need long-term care and monitoring. The quality, quantity and duration of care provision could be a factor in care burden which includes emotional, social, physical and financial burden experienced by the carer of a dependent family member [8,9].

The additional caregiving needs might also affect family caregivers' quality of life (QoL). QoL is a multi-faceted construct that encompasses physical health, psychological health, social relationships and the environment [10]. Those caregivers who have significant burden can have less time for personal activities, less sleep, emotional stress, less

social interaction and problems with work or home responsibilities. These can impact on various aspects of their QoL. In contrast, those with less burden might be more likely to keep up their physical and psychological health when they take care of others [11,12].

This is especially important for the BMT context, since family involvement can be intense and long lasting in the BMT process, which may impact QoL of the caregiver. But patient experiences while in the care of the caregiver can differ based on the clinical condition of the patient, length of time in a caregiver's care, family support and health care environment [13]. Therefore, it is important to measure not only the care burden but also QoL, as can give a better understanding of the experiences of family caregivers of BMT patients.

Research Objective

To assess the level of care burden and QoL and determine the association between care burden and QoL among family caregivers of bone marrow transplant patients at the Armed Forces Bone Marrow Transplant Center, Rawalpindi.

METHODOLOGY

Study Design

The cross-sectional correlational study design was used to look at the relationship between the care burden and the quality of life (QoL) of family caregivers of patients who underwent bone marrow transplantation (BMT). The data were gathered only once during the study period, thus, the burden of the caregiver, quality of life (QoL) and the relationship between the two were measured rather than assessed as a cause and effect.

Study Setting

The study was carried out at Armed Forces Bone Marrow Transplant Center (AFBMTC), Rawalpindi being a special specialized tertiary care centre offering all BMT and hematological disorders related services to the patients. The center offers multi-speciality transplantation and post-transplantation services and caters to patients and families from across the country in Pakistan.

Study Population

This study involved family caregivers who were actively involved in day-to-day care and support for BMT patients. Family caregivers were parents, spouses, siblings, and adult children who helped with medication administration, symptom monitoring, activities of daily living, and emotional support while the patient was hospitalized and after discharge.

Study Duration

The study was conducted for 10 months (February to August 2025) and the data collection was done during May-July 2025.

Sample Size and Sampling Technique

Sample size was determined by a biostatistician's help. From records from the hospital statistics office, the estimated number of caregivers over the past 6 months was about 300. The prevalence, or the response rate in this particular study population, were not applicable, so the assumption of a 50% response proportion was used in order to allow for the maximum sample size to be estimated. The initial sample size was determined to be 169 with a 95% confidence level and 5% margin of error. Because of the 20% attrition or non-response (roughly 33 additional family caregivers), the final sample size requirement was 202 family caregivers. A consecutive sampling technique was used to recruit eligible family caregivers attending the BMT center. Participants were recruited using the inpatient and outpatient transplant units by clinical staff. Caregivers eligible for recruitment were approached in turn during hospitalization, discharge and after hospital. The researcher presented the study procedures to the potential participants and informed consent was taken before the data collection.

Eligibility Criteria

The study included male and female family members 18 years of age or older who cared for a post-BMT patient for a minimum of one month, who were willing to participate and gave informed consent. Family caregivers were also excluded where they cared for more than one patient at a time or where they were professional caregivers or formally assigned attendants to patients instead of family members.

Study Variables

Care burden among family caregivers was considered the independent variable and the dependent variable was QoL. Caregiver age, health status, socioeconomic status, duration of caregiving, relationship with patient, educational level, available support systems and severity of patient's condition were potential confounding factors.

Data Collection Instruments

A structured questionnaire with a demographic section and two standard instruments, Zarit Burden Interview (ZBI) and QOL-FV was used for data collection.

Demographic and Caregiving Characteristics

The demographic section elicited data on the age, gender, marital status, educational level, employment status, relationship of the caregiver to the BMT recipient, weekly work hours, length of time caregiving, and previous caregiving experience of the caregiver.

Zarit Burden Interview

The ZBI was used to measure caregiver burden as developed by Zarit et al. It has a total of 22 items that measure various facets of caregiving stress. The questions are each scored on a 5-point Likert-scale (0 = never; 4 = nearly always), and the total score ranges from 0 to 88, with higher scores reflecting higher caregiver burden. In this study, the level of the burden to the caregiver was divided into three groups. A score of 0–20 indicated low burden and minimal impact, a score of 21–40 indicated moderate burden and a noticeable impact, while a score of 41–88 indicated high burden and severe impact. The ZBI evaluates the impact of being a caregiver—stress, social problems, financial issues, emotional strain, and more.

Quality of Life–Family Version

The Ferrell and Grant's QOL-FV was used to measure caregiver QoL. This instrument measures several aspects of care giver well-being including physical, psychological, social/family and spiritual. Items are scored on a 0–10 scale, with higher scores associated with higher QoL, and then reverse scored for negatively worded items. To use for the present study, the total QOL-FV score was rescaled to range from 0–270. The QoL was segmented into three levels: 0-90 (good well-being, high level of QoL); 91-180 (moderate level of QoL, some difficulties); 181-270 (severe problems, low level of QoL).

Validity and Reliability

The data collection tools were piloted by a panel of experts among which is the supervisor, co-supervisor, research team members, biostatistician and experts in quantitative research methods. Questionnaires were translated into Urdu by a professional translator to make them conceptually and linguistically equivalent. The translated tools were then checked by five subject area experts for clarity, relevance, and cultural appropriateness. The instruments were piloted with 10% (20 participants) prior to the main data collection. The Content Validity Index (CVI) was used to determine the content validity. The ZBI had an S-CVI/Ave of 0.89 and the QOL-FV had an S-CVI/Ave of 0.91, which both showed excellent content validity. An internal consistency test (Cronbach's alpha) was conducted during the pilot study. The ZBI showed good reliability ($\alpha = 0.912$), with the subjective and objective burden subscale reliability scores of $\alpha = 0.832$ and $\alpha = 0.847$, respectively. The overall internal consistency of the QOL-FV was good ($\alpha = 0.879$). The psychological distress domain had $\alpha = 0.615$, and the other domains of QoL had acceptable to good reliability.

Data Collection Procedure

Ethical and organizational approval was obtained and data collection began. Family caregivers eligible were identified in the inpatient and outpatient BMT units. The researcher clearly communicated the purpose, procedures, potential risks, and participants' rights using language that is understandable. All participants gave written informed consent prior to their participation. The study questionnaire was employed in the collection of data through face-to-face interviews. The interviews took about 15-30 minutes. Completed questionnaires were checked for completeness and securely stored. Paper-based records were stored in a locked area and only the principal researcher had access to these records and electronic data were password protected.

Data Management & Statistical Analysis

All data were coded, entered, cleaned and analyzed by IBM SPSS Statistics version 26. Participant characteristics and study variables were summarized using descriptive statistics. Continuous variables were presented as mean ± SD or median (IQR), as appropriate, while categorical variables were presented as frequencies and percentages. Pearson's correlation coefficient was used to examine the relationships between caregiver burden and QoL. The group comparisons were made using ANOVA, and linear regression was carried out to find factors associated with CB and QoL, after adjusting for possible confounders. The statistical assumptions were checked prior to analysis. All tests were performed as two-tailed and p-value < 0.05 were regarded as statistically significant.

Ethical Considerations

Approval for data collection was obtained prior to data collection (IRB/organizational approval No. Re 584-AAA-ERC-AFPGMI). All the participants were fully informed about the study and written informed consent was obtained. It was voluntary participation, and confidentiality and anonymity were kept by coding data and by keeping the data in a secure place. Participants were allowed to drop out at any time, with no penalties incurred. The study was done with the adherence to the Declaration of Helsinki and the relevant ethical principles.

RESULTS

Table 1 presents the demographic characteristics of 202 family caregivers. Females were predominant (110, 54.5%), while 92 (45.5%) were males. Most caregivers were married (55, 27.2%), employed (59, 29.2%), and had a master's degree or higher (48, 23.8%). Parents were the most common caregivers (45, 22.3%), followed by siblings (42, 20.8%).

Table 1. Demographic Characteristics of Family Caregivers (N = 202)

Variable	Category	Frequency (n)	Percentage (%)
Gender	Female	110	54.5
	Male	92	45.5

Marital status	Married	55	27.2
	Single	52	25.7
	Divorced	51	25.2
	Widowed	44	21.8
Employment status	Employed	59	29.2
	Housewife	52	25.7
	Unemployed	46	22.8
	Retired	45	22.3
Education	No formal education	43	21.3
	Primary	36	17.8
	Secondary	37	18.3
	Bachelor's	38	18.8
	Master's or higher	48	23.8
Relationship to patient	Parent	45	22.3
	Sibling	42	20.8
	Other	41	20.3
	Spouse	39	19.3
	Child	35	17.3

Table 2 shows the item-level caregiver burden measured by the ZBI. Mean item scores ranged from 1.65 ± 1.06 for uncertainty about handling caregiving duties to 1.92 ± 1.08 for doubting the ability to provide the best care. Other relatively higher scores included feeling mainly responsible for the care recipient (1.90 ± 1.09) and feeling uncomfortable having friends over (1.86 ± 1.08), indicating notable emotional and social burden among caregivers.

Table 2. Item-Level Descriptive Statistics of Caregiver Burden Measured by the Zarit Burden Interview (N = 202)

ZBI Item	Never (n;%)	Rarely (n;%)	Sometimes (n;%)	Frequently (n;%)	Nearly always (n;%)	Mean ± SD
Stress balancing caregiving with other duties	19 (9.4)	56 (27.7)	75 (37.1)	42 (20.8)	10 (5.0)	1.84 ± 1.02
Embarrassment due to care recipient's behavior	31 (15.3)	59 (29.2)	60 (29.7)	40 (19.8)	12 (5.9)	1.72 ± 1.13
Anger/frustration while caregiving	26 (12.9)	71 (35.1)	51 (25.2)	45 (22.3)	9 (4.5)	1.70 ± 1.09
Caregiving affects you negatively	20 (9.9)	71 (35.1)	62 (30.7)	42 (20.8)	7 (3.5)	1.73 ± 1.01
Fear about the future	25 (12.4)	48 (23.8)	69 (34.2)	56 (27.7)	4 (2.0)	1.83 ± 1.03
Feeling emotionally strained	24 (11.9)	55 (27.2)	68 (33.7)	48 (23.8)	7 (3.5)	1.80 ± 1.04
Lack of privacy	26 (12.9)	62 (30.7)	67 (33.2)	39 (19.3)	8 (4.0)	1.71 ± 1.05
Social life suffering	34 (16.8)	46 (22.8)	68 (33.7)	40 (19.8)	14 (6.9)	1.77 ± 1.15
Feeling uncomfortable having friends over	21 (10.4)	58 (28.7)	63 (31.2)	48 (23.8)	12 (5.9)	1.86 ± 1.08
Feeling loss of control	26 (12.9)	54 (26.7)	66 (32.7)	47 (23.3)	6 (3.0)	1.74 ± 1.06
Wishing to leave caregiving to someone else	22 (10.9)	64 (31.7)	63 (31.2)	43 (21.3)	10 (5.0)	1.78 ± 1.06
Uncertainty about handling caregiving duties	31 (15.3)	59 (29.2)	70 (34.7)	33 (16.3)	9 (4.5)	1.65 ± 1.06
Feeling you should do more	26 (12.9)	48 (23.8)	69 (34.2)	45 (22.3)	11 (5.4)	1.81 ± 1.11
Doubting ability to	23 (11.4)	50 (24.8)	58 (28.7)	63 (31.2)	8 (4.0)	1.92 ±

provide the best care						1.08
Overall sense of burden	16 (7.9)	72 (35.6)	62 (30.7)	44 (21.8)	8 (4.0)	1.78 ± 1.00
Care recipient asks for more help than needed	22 (10.9)	60 (29.7)	67 (33.2)	47 (23.3)	6 (3.0)	1.78 ± 1.02
Caregiving leaves little time for self	23 (11.4)	64 (31.7)	63 (31.2)	42 (20.8)	10 (5.0)	1.76 ± 1.06
Care recipient is dependent on you	24 (11.9)	58 (28.7)	63 (31.2)	52 (25.7)	5 (2.5)	1.78 ± 1.04
Health suffering due to caregiving	23 (11.4)	61 (30.2)	62 (30.7)	46 (22.8)	10 (5.0)	1.80 ± 1.07
Caregiving interferes with personal plans/goals	28 (13.9)	64 (31.7)	59 (29.2)	42 (20.8)	9 (4.5)	1.70 ± 1.08
Feeling mainly responsible for care recipient	20 (9.9)	58 (28.7)	58 (28.7)	54 (26.7)	12 (5.9)	1.90 ± 1.09
Feeling unable to continue caregiving	28 (13.9)	56 (27.7)	60 (29.7)	48 (23.8)	10 (5.0)	1.78 ± 1.11
Insufficient financial resources	23 (11.4)	61 (30.2)	67 (33.2)	48 (23.8)	3 (1.5)	1.74 ± 1.00

Figure 1 demonstrates the overall response distribution for caregiver burden. Most caregivers reported experiencing burden-related concerns sometimes (67, 33.2%), followed by rarely (53, 26.2%) and frequently (46, 22.8%). A smaller proportion reported these experiences never (24, 11.9%) or nearly always (12, 5.9%).

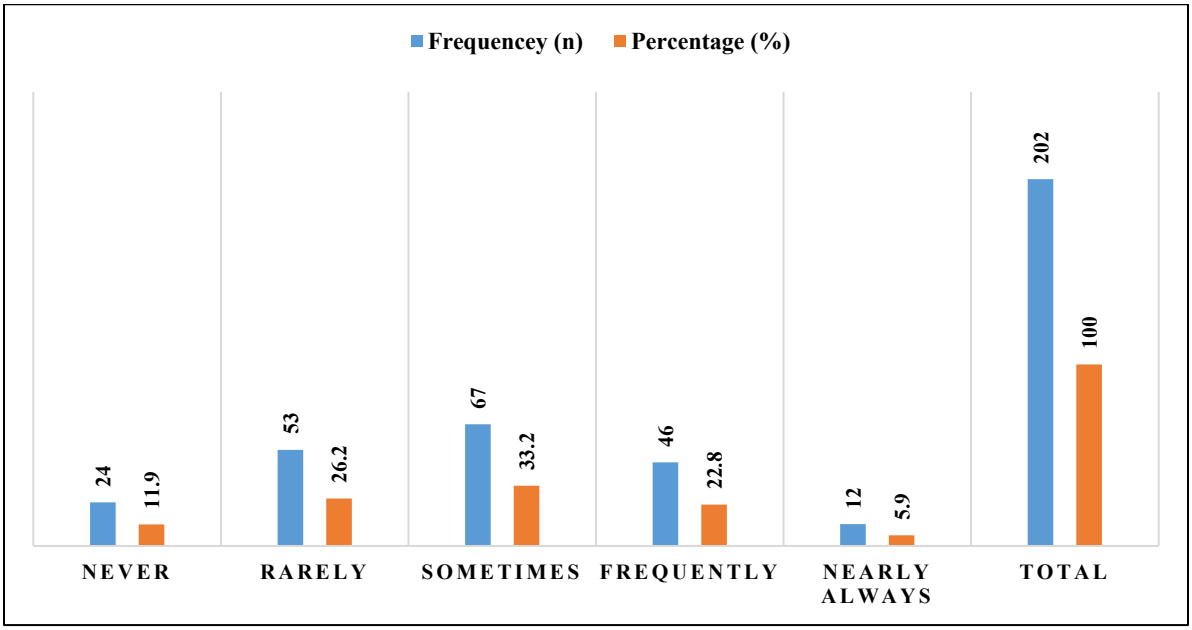

Figure 1. Overall Caregiver Burden Based on the Zarit Burden Interview (N = 202)

Table 3 presents the descriptive statistics of caregiver QoL. The overall QOL-FV score was 222.91 ± 41.26. Mean scores across the physical, psychological, social, and spiritual domains were generally around 6 points, with psychological and social well-being showing overall mean scores of 6.12 ± 1.92 and 6.21 ± 1.80, respectively.

Table 3. Descriptive Statistics of QoL among Family Caregivers (N = 202)

Domain	QoL item	Mean ± SD
Physical well-being	Fatigue	5.87 ± 1.87
	Appetite changes	6.05 ± 1.80
	Pain or aches	6.09 ± 1.68
	Sleep changes	5.96 ± 1.70
	Overall physical health	5.98 ± 1.75

Psychological well-being	Coping with disease/treatment	6.13 ± 1.78
	Overall QoL	5.84 ± 1.73
	Happiness	6.11 ± 1.77
	Control over life	6.14 ± 1.83
	Life satisfaction	5.97 ± 1.74
	Concentration/memory	6.14 ± 1.72
	Feeling useful	6.17 ± 1.87
	Distress at diagnosis	5.86 ± 1.74
	Distress from treatment	6.02 ± 1.76
	Distress after treatment	5.90 ± 1.78
	Anxiety	6.21 ± 1.88
	Depression	6.04 ± 1.78
	Fear of second cancer	6.02 ± 1.76
	Fear of recurrence	5.90 ± 1.82
	Fear of metastasis	6.08 ± 1.82
	Overall psychological well-being	6.12 ± 1.92
Social well-being	Family distress	5.96 ± 1.77
	Support from others	6.01 ± 1.81
	Interference with relationships	6.05 ± 1.78
	Interference with intimacy	5.87 ± 1.76
	Interference with employment	6.17 ± 1.71
	Interference with activities at home	6.06 ± 1.80
	Isolation	6.05 ± 1.83
	Financial burden	5.83 ± 1.79
	Overall social well-being	6.21 ± 1.80
Spiritual well-being	Religious support	5.90 ± 1.67
	Personal spiritual support	6.10 ± 1.87
	Uncertainty about future	6.10 ± 1.78
	Positive changes in life	5.98 ± 1.79
	Purpose/mission for life	6.01 ± 1.78
	Hopefulness	6.05 ± 1.70
	Overall spiritual well-being	5.97 ± 1.83
Overall QoL	QOL-FV total score	222.91 ± 41.26

Figure 2 shows the categorical distribution of QoL among caregivers. The largest proportion had moderate QoL (77, 38%), followed by good QoL (65, 32%), poor QoL (40, 20%), excellent QoL (16, 8%), and very poor QoL (12, 6%).

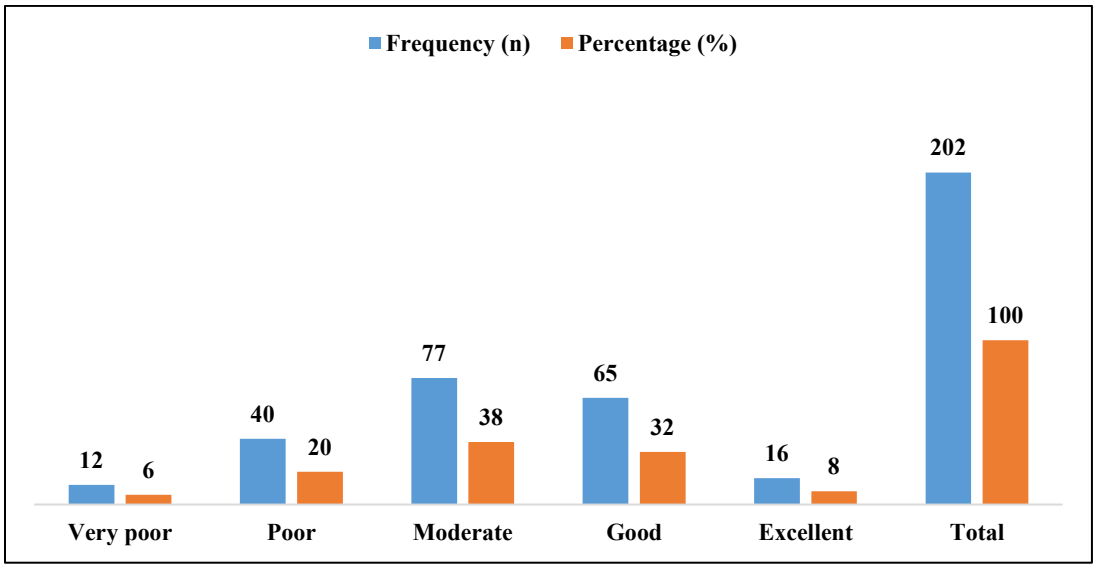

Figure 2. Categorical Distribution of QoL among Family Caregivers (N = 202)

Table 4 demonstrates a strong, statistically significant negative correlation between caregiver burden and QoL ($r = -0.798$, $p < .001$). This indicates that caregivers experiencing greater burden tended to report lower QoL.

Table 4. Pearson Correlation between Caregiver Burden and QoL (N = 202)

Variables	QoL (QOL-FV)	Caregiver burden (ZBI)
QoL (QOL-FV)	1.000	−0.798*
Caregiver burden (ZBI)	−0.798*	1.000

Note: *$p < .001$, two-tailed. ZBI = Zarit Burden Interview; QOL-FV = QOL-FV.

Table 5 presents the linear regression analysis. Caregiver burden was a significant negative predictor of QoL ($B = -2.019$, $\beta = -0.798$, $t = -18.749$, $p < .001$). The model explained 63.7% of the variance in QoL ($R^2 = 0.637$), indicating that higher caregiver burden was strongly associated with poorer QoL.

Table 5. Linear Regression Analysis of Caregiver Burden as a Predictor of QoL (N = 202)

Predictor	B	SE	β	t	p-value	95% CI for B
Constant	305.441	4.738	—	64.469	<.001	266.098–314.783
Caregiver burden (ZBI)	−2.019	0.108	−0.798	−18.749	<.001	−2.231 to −1.807

Note: Model statistics: $R = 0.798$; $R^2 = 0.637$; adjusted $R^2 = 0.635$; SE of estimate = 24.906; Durbin–Watson = 2.055; $F(1, 200) = 351.53$, $p < .001$.

DISCUSSION

The present study revealed that there was a significant caregiving burden amongst the family caregivers of BMT patients at AFBMTC, Rawalpindi. The highest mean ZBI scores were for doubting the ability to provide the most beneficial care (1.92 ± 1.08), feeling mainly responsible for the care recipient (1.90 ± 1.09), and feeling uncomfortable having friends over (1.86 ± 1.08) at the item level. Such results found that the emotional responsibility and the social life disruption of caregivers. These concerns have been expressed by HSCT caregivers. Akgul and Ozdemir (2014) found the mean ZBI score to be 28.41 ± 13.90, with the number of caregiving activities, education level and income level showing significant relationships with the burden [14]. Similarly, the duration of caregiving, the amount of caregiving time spent per day, complications, relapse, and the presence of co-caregivers have been identified as factors associated with burden in previous research [15].

The distribution of individual burden items in the current study also indicates that caring has an impact on the personal health and functioning of the caregivers. The mean scores for health suffering due to caregiving, limited time for self, difficulty balancing with other responsibilities, and interference with personal plans and goals were 1.80 ± 1.07, 1.76 ± 1.06, 1.84 ± 1.02, and 1.70 ± 1.08, respectively. These results corroborate with evidence demonstrating that HSCT caregiving is related to disruption of normal routines and responsibilities. In a sample of 193 caregivers with HCT, Waldman et al. (2021) identified clinically significant anxiety level in 46.6% and depression in 16.1%, with psychological distress correlated with lower physical health and less leisure time. Likewise, qualitative research has revealed that caregivers' work and home schedules are disrupted, their uncertainty, and their struggles to adjust to various patient needs during transplantation [16].

The overall QOL-FV score was 222.91 ± 41.26, with the mean domain scores being 5.98 ± 1.75 for physical well-being, 6.12 ± 1.92 for psychological well-being, 6.21 ± 1.80 for social well-being, and 5.97 ± 1.83 for spiritual well-being. There were similar scores on the different domains, indicating that caregiver challenges were not just about physical health. In a large study of 849 caregivers 6 years after HCT, Jamani et al. (2018) observed that about 20% of caregivers reported poor QoL compared to population norms and noted the following as important factors: age, sex, education, recipient QoL, relapse, and ongoing immunosuppression [17]. The results of the present study thus further confirm that the well-being of the caregiver is a key factor during the entire trajectory of transplantation, not just during the immediate post-transplant period.

The most significant result was the negative correlation between the caregiver's burden and QoL. There was a strong and negative correlation between caregiver burden and QoL in this study ($r = -0.798$, $p < .001$), suggesting that a higher level of burden was associated with significantly poorer QoL. The regression analysis also revealed that caregiver burden was a significant negative predictor of QoL ($B = -2.019$, $\beta = -0.798$, $t = -18.749$, $p < .001$) accounting for 63.7% of the variance in QoL ($R^2 = .637$). The negative relationship between burden and QoL was similar to that reported by Xie et al. (2021) in 116 HSCT caregiver–patient dyads [15]. It is also similar to the findings of Amonoo et al. (2023) that approach-oriented coping positively correlated with QoL ($\beta = 0.526$, $p = .002$) while avoidant coping was negatively correlated with QoL ($\beta = -1.631$, $p < .001$) [18].

The strong correlation that was noticed in the present study has clinical significance. Caregiver burden explains 63.7% of the variability in QoL in the unadjusted regression model, which suggests that assessing caregiver burden should be part of routine supportive care after BMT. It is supported by intervention research evidence. In a randomized clinical trial, El-Jawahri et al. (2020) found that the BMT-CARE psychosocial intervention improved caregiver QoL

(B = 6.11, 95% CI 3.50–8.71, p < .001) and reduced caregiving burden (B = −6.02, 95% CI −8.49 to −3.55, p < .001) compared with usual care [19]. This finding justifies structured caregiver education, psychological support, coping interventions and opportunities for respite in BMT care.

In conclusion, the present study validates the significant emotional, physical, social, and psychological burdens of family care of BMT patients and the strong link between high caregiver burden and low QOL. The correlation and regression association between caregiver burden and other measures were particularly strong ($r = -0.798$; $\beta = -0.798$) to not be considered a secondary problem but as an important part of the full transplant care. However, the association of the burden with reduced QoL in the present study should not be interpreted as evidence of a causal relationship, as the study was cross sectional. In the future, more longitudinal studies should be conducted in multiple centers across the country to identify changes in caregiver burden and QoL from the point of pre-transplant to hospitalization, discharge and post transplantation follow-up phase as well as to assess culturally appropriate interventions. This research could be helpful in defining supportive-care pathways based on the caregiver's perspective in the framework of Pakistani BMT services.

Strengths and Weakness of Study

One strength of this study is the purposeful assessment of the relationship between caregiver burden and QOL among a relatively adequate sample of family caregivers of BMT patients in a specialized transplant center using standardized instruments (ZBI and QOL-FV). Data reliability and content validity were enhanced by the use of validated questionnaires, expert review, pilot testing and assessment of internal consistency. The study also used suitable descriptive and inferential statistics such as Pearson correlation and linear regression analyses, and showed that there was a strong and statistically significant correlation between the caregiver burden and the QoL. But the following restrictions must be kept in mind. The cross sectional design does not allow a causal relationship to be established between caregiver burden and QoL. The study was performed in one centre and may not be representative of other hospitals and regions of Pakistan. However, the sampling method could also select for the "extreme" and recall or social desirability bias may also have influenced caregiver responses. Furthermore, this study did not provide detailed longitudinal evaluation of burden and QoL at various stages of transplantation and the scoring and categorization of QoL needs to be clarified to ensure uniformity with the original instrument.

CONCLUSION

The findings of this study suggest that the family caregivers of bone marrow transplant patients have high caregiving burden and this is strongly related to lower QoL. They suggest that caregiving can impact caregivers in physical, psychological, social and emotional ways, especially when it comes to increased responsibility, upended personal and social lives and worries about the quality of care. The results of this study underscore the need to acknowledge the family caregiver as an integral part of the BMT care team. Assessment of the caregiver burden and QoL regularly, and providing caregivers with appropriate education, psychological support, social support, and respite can help enhance the caregiver's well-being. Longitudinal and multi-center studies are suggested in future to further investigate how caregiver burden and QoL change during the transplant journey and to assess how interventions to support caregivers work.

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