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Original Article

Caregivers' Burden and Mental Health of the Caregivers of β-Major Thalassemia Patients: Mediating Role of Religious Coping

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ABSTRACT

Background: Caregiver burden among those caring for patients with thalassemia major in Pakistan poses significant psychological challenges. The role of religious coping mechanisms in alleviating psychological distress and enhancing well-being among caregivers has been highlighted in prior research, suggesting a complex interplay between caregiver strain, coping strategies, and mental health outcomes.

Objective: This study aims to investigate the relationships between caregiver burden, positive religious coping, and mental health outcomes, specifically psychological well-being and distress, among caregivers of thalassemia patients in the Twin cities of Islamabad and Rawalpindi.

Methods: Employing a cross-sectional design, the study included 180 caregivers of thalassemia patients, recruited through non-probability purposive sampling from major thalassemia centers and hospitals in Islamabad and Rawalpindi. Data were collected using the Zarit Caregiver's Burden Scale, the Brief Religious Coping Scale, and the Mental Health Inventory. Structural Equation Modeling (SEM) was utilized to analyze the data, using SPSS and AMOS software, with a focus on the mediating role of positive religious coping between caregiver burden and mental health outcomes.

Results: The analysis revealed that caregiver burden significantly predicted the use of positive religious coping ($\beta = .32$, $p < .001$) and was negatively associated with psychological well-being ($\beta = -.33$, $p < .001$) while positively associated with psychological distress ($\beta = .23$, $p < .01$). Positive religious coping positively influenced psychological well-being ($\beta = .28$, $p < .01$) and negatively influenced psychological distress ($\beta = -.21$, $p < .05$). The model explained 38.2% of the variance in psychological well-being and 34.1% in psychological distress.

Conclusion: The findings underscore the significant impact of caregiver burden on the mental health of caregivers, with positive religious coping serving as a beneficial mediating factor. Enhancing positive religious coping among caregivers may be a viable intervention strategy to improve their mental health outcomes.

Keywords: caregiver burden, religious coping, psychological well-being, psychological distress, thalassemia, SEM analysis, mental health outcomes, caregiver support.

INTRODUCTION

In developing countries such as Pakistan, the high child mortality rate presents a significant challenge, compounded by various factors including genetic and congenital disorders. Thalassemia, a genetic disorder characterized by the reduced synthesis of hemoglobin chains, is prevalent in Pakistan, where early marriages, consanguinity, and low literacy rates contribute to its transmission (1). The country reports approximately forty thousand cases of β-major thalassemia and nearly eight million carriers of the thalassemia trait (3). The management of thalassemia, which often requires frequent blood transfusions, imposes substantial financial and social burdens on families (5,7). Despite the availability of treatments that extend life and alleviate some of the physical burdens, the psychological and social impacts on families, particularly caregivers, are profound.

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Caregivers of thalassemia patients face significant challenges, including socioeconomic stress and psychological distress marked by feelings of isolation, loneliness, and guilt. The burden of caregiving negatively impacts their quality of life and mental health, necessitating effective coping mechanisms (9). In this context, religious coping emerges as a crucial strategy among caregivers. In studies focusing on Asian Indian and Pakistani communities, religious faith frequently serves as a primary coping mechanism, providing emotional support and resilience during challenging times (10,11). Interestingly, the literature suggests that spouse caregivers often experience greater psychological strain compared to adult children or children-in-law, with heightened symptoms of depression and reduced psychological well-being (12).

Internationally, research has established a link between the caregiver burden associated with thalassemia and mental health issues such as depression, particularly under conditions of lower income and frequent medical interventions (13,14). Positive religious coping strategies have been shown to correlate with lower caregiver burden and enhanced well-being (15,17,18). However, the dynamics of religious coping and mental health are complex, with the burden of caregiving for thalassemia generally categorized as moderate, yet exacerbated by financial and caregiving responsibilities (16,19). Negative coping strategies can exacerbate anxiety, whereas positive strategies can significantly improve overall well-being (18-23).

This study aims to explore the intricate relationship between caregiver burden, religious coping, and the mental health of caregivers of thalassemia patients. By focusing on these aspects, it seeks to understand the comprehensive impact of caregiving on mental, psychological, financial, and social well-being. It is hypothesized that caregivers employing positive religious coping mechanisms will experience better mental health outcomes, demonstrating lower levels of psychological distress and higher levels of psychological well-being. Additionally, positive religious coping is anticipated to mediate the relationship between caregiver burden and mental health outcomes for caregivers of thalassemia patients. This research underscores the importance of recognizing and supporting effective coping strategies to mitigate the extensive demands placed on caregivers, ultimately aiming to enhance their quality of life and mental health.

MATERIAL AND METHODS

The study employed a correlational (cross-sectional) design to examine the relationship between caregiver burden, the role of positive religious coping, and the mental health of caregivers of thalassemia patients in the Twin cities of Islamabad and Rawalpindi. Conducted over a four-month period from October 2023 to January 2024, the research received approval from the institutional review board of Bahria University, Islamabad, and adhered to the American Psychological Association's ethical guidelines. The study was not supported by any external funding sources.

Participants consisted of 180 caregivers of thalassemia patients, comprising 75 men and 105 women, selected through non-probability purposive sampling from various thalassemia centers and hospitals regardless of their age and gender. Inclusion criteria targeted individuals responsible for at least one thalassemia major patient for more than six months and who were proficient in Urdu. Caregivers with diagnosed mental or medical health conditions, other than thalassemia minor, were excluded from participation.

Data collection involved securing permissions from the management of multiple thalassemia-related institutions including the Jamila Sultana Foundation, Pakistan Thalassemia Society, PIMS Hospital, and Benazir Bhutto Hospital. Caregivers accompanying patients for blood transfusions at these locations were approached. Instruments used for data gathering included the Zarit Caregiver's Burden Scale, the Brief Religious Coping Scale, and the Mental Health Inventory, all of which had authorized Urdu versions (24-30). Each participant was informed about the nature and purpose of the research, their right to withdraw at any point, and the confidentiality of their responses, which were solely for research use. Participants were also assured that their participation would not result in any physical or psychological harm. Data from literate participants were collected via self-administered questionnaires, while those unable to read participated through face-to-face interviews (1, 17, 21).

Data analysis was performed using SPSS version 27 for descriptive and reliability analyses to assess the demographic characteristics and the psychometric properties of the study variables, respectively. The mediating role of positive religious coping between caregiver burden and mental health was analyzed using AMOS version 25.0, employing Structural Equation Modeling (SEM). A significance threshold was set at a p-value of less than 0.05, indicating statistical significance for the analyses conducted.

RESULTS

In the investigation of the relationships between caregiver burden, positive religious coping, psychological well-being, and psychological distress among caregivers of thalassemia patients, significant findings emerged as detailed in the structured equation modeling analysis (see Table 4). Caregiver burden positively influenced the adoption of positive religious coping mechanisms with a

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standardized beta coefficient of .32 (p<.001), suggesting a moderate and significant effect. This indicates that higher levels of perceived burden are associated with more frequent engagement in religious coping strategies by caregivers.

The impact of caregiver burden on psychological well-being was also significant, demonstrating a negative relationship as indicated by a beta coefficient of-.33 (p<.001). This suggests that increased caregiver burden is associated with decreased psychological well-being among caregivers. Similarly, caregiver burden was found to have a significant, albeit somewhat weaker, positive association with psychological distress, as denoted by a beta coefficient of .23 (p<.01).

Table 1: Descriptive Statistics of the Demographic Characteristics of the Sample (N=180)

Variable	Frequency (f)	Percentage (%)	Mean (M)	Standard Deviation (SD)
Age			36.18	9.986
Education			8.77	4.439
Monthly Income (PKR)			34,700	22,334
Gender				
Male	75	41.66		
Female	105	58.33		
Area				
Rural	110	61.11		
Urban	70	38.88		
Relation with Patient				
Father	54	30.00		
Mother	103	57.22		
Brother	6	3.33		
Sister	10	5.55		
Other	2	1.11		
Years of Caregiving			7.5	5.5
Time Since Diagnosis (years)			2.45	1.6

Table 2: Descriptive and Reliability Analysis of Study Variables (N=180)

Variables	Number of Items (K)	Mean (M)	Standard Deviation (SD)	Actual Range	Potential Range	Cronbach's Alpha (α)
Caregiver Burden	12	18.10	8.767	3-41	0-48	.808
Positive Religious Coping	7	26.55	3.072	7-28	7-28	.882
Mental Health	38	140.37	16.29	101-175	38-228	.921
Psychological Wellbeing	14	44.72	13.9	21-66	14-84	.902
Psychological Distress	24	72.35	18.59	31-117	24-144	.885

Table 3: Fit Indices for Structural Equation Modeling (SEM) of Caregiver Burden, Positive Religious Coping, and Mental Health

Model	Chi-square (χ^2)	Degrees of Freedom (df)	χ^2/df	Goodness of Fit Index (GFI)	Comparative Fit Index (CFI)	Non-Normed Fit Index (NNFI)	Root Mean Square Error of Approximation (RMSEA)	Standardized Root Mean Square Residual (SRMR)
Initial Model	23.21	9	2.56	.94	.91	.92	.07	.06

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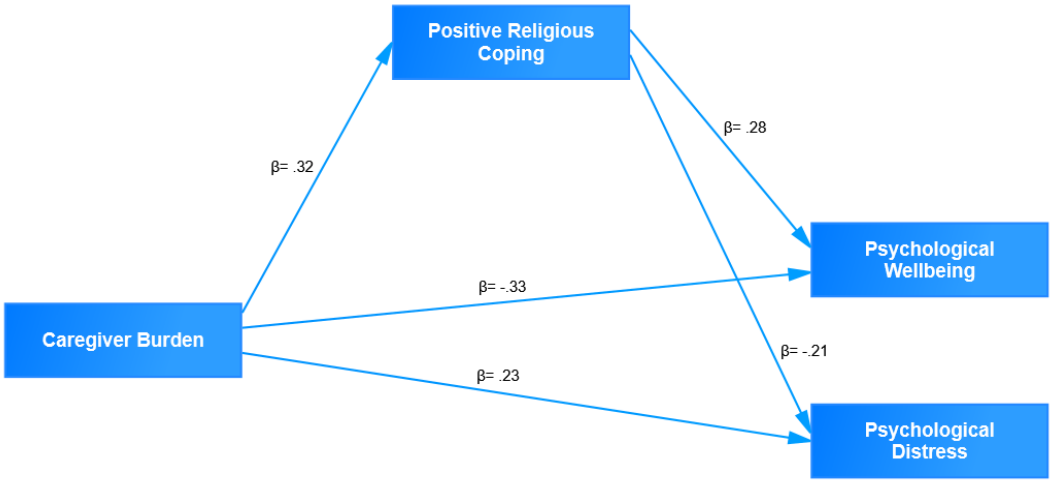

Figure 1 Empirical Results from a Complex Multivariate Model Representing Standardized Regression Coefficients.

Table 4: Standardized Estimates of Direct Effects (N=180)

Variable	Positive Religious Coping	Psychological Wellbeing	Psychological Distress
	β	SE	β
Caregiver Burden	.32***	0.17	0.33***
Positive Religious Coping	-	-	0.28**
Total R^2	.311		.382

Table 5: Standardized Estimates of Indirect Effects Through Positive Religious Coping (N = 180)

Variable	Psychological Wellbeing	Psychological Distress
	β	SE
Caregiver Burden	0.09**	0.07

Positive religious coping demonstrated a significant positive effect on psychological well-being, with a beta coefficient of .28 (p<.01), and a negative effect on psychological distress, reflected by a beta coefficient of-.21 (p<.05). These findings suggest that engagement in positive religious coping strategies may buffer the negative psychological impacts associated with caregiver burden (see Table 5 for indirect effects).

The total variance explained by the model for psychological well-being was 38.2%, and for psychological distress, it was 34.1%, as indicated by the R^2 values in Table 4. These results highlight the substantial role that religious coping plays in mediating the effects of caregiver burden on mental health outcomes.

The goodness of fit for the model was robust, with a χ^2/df ratio of 2.56, GFI of .94, CFI of .91, NNFI of .92, RMSEA of .07, and SRMR of .06, suggesting that the model adequately fits the data (Figure 1 illustrates these relationships). These indices collectively affirm the statistical validity of the relationships modeled in this study, supporting the hypothesized pathways between caregiver burden, religious coping, and mental health outcomes among caregivers of thalassemia patients. This comprehensive analysis underscores the importance of religious coping mechanisms in mitigating the negative impacts of caregiving burdens on psychological health.

DISCUSSION

The findings of this study corroborate earlier research, affirming that caregiver burden significantly predicts both positive religious coping and psychological distress, while inversely affecting psychological well-being. This dual role of caregiver burden highlights the complex dynamics caregivers navigate, balancing stress and coping mechanisms to maintain their mental health. Notably, the study also identified that positive religious coping significantly enhances psychological well-being and mitigates psychological distress (22, 30), aligning with the hypothesis that positive religious coping acts as a mediating factor between caregiver burden and mental health outcomes.

Previous studies, such as those by Anum & Dasti (22) and Chen et al. (24), have similarly reported a negative correlation between caregiver burden and both mental and physical health, thereby reinforcing the general consensus that higher caregiver burdens are

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detrimental to health. This detrimental impact extends to psychological symptoms including anxiety, depression, and irritability, as illustrated by the research of Zhang et al. (25). Furthermore, the emotional strain of caregiving is often compounded by its disruptive effects on family dynamics and overall well-being, a factor explored by Patel et al. (26).

However, in the face of these challenges, positive religious coping emerges as a critical resource, as evidenced by the significant mediating effects it exhibits on the relationship between caregiver burden and mental health outcomes. This finding is consistent with the literature on caregiving in other contexts, such as dementia, where spiritual coping strategies significantly buffered the mental health impacts of caregiving (30, 31). The preference for positive religious coping over negative coping mechanisms among caregivers of thalassemia patients further underscores the adaptive role of faith-based strategies in managing caregiver stress (8).

The study also illuminated the broader implications of religious beliefs and practices, which are frequently associated with better mental health among family caregivers (27). This association highlights the importance of integrating spiritual care in supportive interventions for caregivers.

The current study is not without limitations. The cross-sectional design, while effective for identifying associations, does not permit causation inference. Future research could benefit from a longitudinal approach to more clearly delineate the cause-and-effect relationships among caregiver burden, religious coping, and mental health outcomes. Additionally, the sample was restricted to caregivers in the Twin cities area, which may limit the generalizability of the findings to other regions or cultural contexts.

Given these insights, it is recommended that future interventions designed to support caregivers include components that foster positive religious coping. Such initiatives could potentially amplify the psychological resilience of caregivers, thereby enhancing their ability to manage the demands of their role. Further studies should also explore the effectiveness of these interventions across different cultural and religious backgrounds to ascertain their broader applicability and impact (28, 31).

CONCLUSION

In conclusion, this study substantiates that caregiver burden significantly predicts increased religious coping and psychological distress, while adversely affecting psychological well-being. Conversely, engaging in positive religious coping fosters better psychological well-being and reduces distress among caregivers, confirming its beneficial role as a mediating factor in the caregiving experience. These findings underscore the critical need for targeted support mechanisms that enhance positive coping strategies among caregivers, ultimately improving their mental health outcomes.

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