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Caregiver Burden, Psychological Well-Being and Coping Strategies of Parents Having Children with Thalassemia

Naveed Alam Khan[1], Dr. Abdur Rashid[2], Misbah Ullah[3] & Kainat Javed[4]

[1] *Lecturer,(IBL) institute of business studies and Leadership, awkum, Email: naveedalam@awkum.edu.pk*
[2] *Assistant Professor, Department of clinical Psychology, SZABIST Islamabad, Email: dr.rashid@szabist-isb.edu.pk*
[3] *CEO New Leaf Rehab Center, Islamabad, Email: misbahkhancr@gmail.com*
[4] *Pakistan Atomic Energy Commission (PAEC) General Hospital, Email: kainatjaved150@gmail.com*

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Corresponding Author:
Naveed Alam Khan
Email:
naveedalam@awkum.edu.pk

ABSTRACT

Thalassemia is a chronic disease caused by a genetic defect that interferes with a child's normal physiological functioning and affects the physica1, emotional, and cognitive wel1-being of individuals and their families. Children with thalassemia have to go to the hospital on a frequent basis for b1ood transfusions. Parents are burdened psychologically because of the expenses, stress, and fear of loss. A total of 100 subjects were se1ected using the convenient samp1ing technique. Data was analyzed by using descriptive statistics to find out the frequencies and percentages of the basic variables. Among the parents of thalassemia children residing in Khyber Pakhtunkhwa, the current study was conducted to determine the relationship between the caregiver burden, coping mechanisms, and psychological well-being of parents of thalassemic children. The Zarit burden interview scale, Jalowiec Coping Scale A, Jalowiec Coping Scale B, and The Warwick-Edinburgh Mental Well Being Scale (WEMWBS) was used. A1l the scales demonstrated good re1iability for the current population. The findings suggest that monthly income was significantly negatively correlated with the caregiver burden of parents of thalassemic children in Khyber Pakhtunkhwa. A significant negative correlation between the level of care giver burden of thalassemic children and Psychological well –being of parents of thalassemic children was also found.

Introduction

The genetic condition of Thalassemia disturbs globin chain synthesis thus creating reduced hemoglobin production and developing hypochromic microcytic anemia (Weatherall, 2010a, 2010b). Children affected by this chronic condition need regular medical assistance through blood transfusions because their care becomes a heavy burden for both patients and their relatives. The physical burden of thalassemia makes children experience social isolation together with restrictions on their activities as well as psychological distress (Weatherall, 2010b). Thalassemia creates substantial psychological challenges to parents by pushing their psyche through financial worries and medical demands that come from nursing their thalassemic child (Majid & Abidi, 2013).

The destructive consequences of Thalassemia afflict both patient individuals and everyone around them. Thalassemia children's parents face substantial psychological burdens which cause depression together with anxiety and feel helpless according to Ghanizadeh (2006) and other research findings. Ashrafizadeh et al. (2016) revealed that the caretakers face extreme adverse effects due to both emotional burdens and monetary strain while administering medical care to their children with thalassemia. Although physical manifestations of the disease receive more research attention scientists have not thoroughly investigated the mental health condition of caregivers. Research on the connections among caregiver burden and psychological health as well as coping strategies for parents of children with thalassemia has not been adequately investigated (Rajput et al., 2015).

This study focuses on explaining the relationships between caregiver burdens together with psychological well-being and coping techniques utilized by parents whose children have thalassemia. This research investigates parents from Khyber Pakhtunkhwa, Pakistan because medical resources are scarce and thalassemia damages the public health of the province. Knowledge from this study enables comprehensive understanding of caregiver psychological challenges and supports intervention development to assist parents who care for their sick children.

Literature Review

Caregiver Burden

Caregiver burden encompasses all the physical as well as emotional and social and financial burdens felt by people who take care of someone living with a chronic illness or disability. Prolonged intensive care requirements place especially high stress on caregivers when their care recipient suffers from thalassemia. The patient's health condition severity together with maintenance time and caregiver's adaptability skills determine the extent of burden they experience (Valizadeh et al., 2014). Thalassemia caregivers particularly parents experience heavy pressure because of their child's recurring medical appointments and high healthcare expenses together with the emotional consequences of their child's health condition (Papastavrou et al., 2012). Research validates that parents who take care of children with enduring health problems like thalassemia display elevated stress symptoms and reduced mental health quality regarding standard child healthcare (Kovacs, 1985; Gillis, 1993).

Studies confirm that caregiving produces negative physical and financial impacts along with psychological stress for caregivers based on findings from Duxbury et al. (2011). Caregivers must spend significant amounts of healthcare costs on medical appointments and treatment while dealing with financial strain due to their caregiver duties. Caregivers experience financial uncertainty especially when work inability or increased caregiving expenses prevent them from supporting themselves (Duxbury et al., 2011). The financial difficulties worsen because children with thalassemia need unpredictable medical treatments including regular blood transfusions (Covinsky et al., 1994).

Psychological Well-Being of Caregivers

A person exhibits psychological well-being when they show positive emotional capabilities which incorporate elements of self-esteem together with stress control and feelings of satisfaction toward life (Burn, 2017). The long-term care responsibilities of thalassemia patients lead caregivers to develop poor psychological states as reported by Ghanizadeh (2006). Being the primary caretaker of a child with illness presents such mental challenges like depression alongside anxiety and emotional fatigue which emerges from feelings of helplessness and guilt related to their child's health condition (Ashrafizadeh et al., 2016). Caregivers struggle to preserve life balance because illness management stress leads to a deterioration of their personal well-being (Kovacs, 1985).

The development of psychological problems is most common among mothers whose children have chronic conditions including thalassemia. When mothers actively engage in child care while showing intense emotions toward their sick children they face increased chances for depression and anxiety compared to fathers as reported in Ashrafizadeh et al. (2016). Multiple research studies indicate that women who act as thalassemia child caregivers experience worse quality of life measures and higher incidence of mental health conditions while caring for these patients than male caregivers do.

Coping Strategies Among Caregivers

Coping serves as the set of techniques which people utilize to handle stress and emotional burdens from troublesome events according to Lazarus and Folkman (1984). Children with thalassemia lead caregivers to experience multiple types of emotional and physical distress. To protect their psychological well-being caregivers need to develop effective coping strategies because these help them manage their caregiver responsibilities (Folkman & Moskowitz, 2004).

The practice of coping techniques includes two recognized approaches which are problem-focused strategies and emotion-focused techniques. The process of problem-focused coping includes solutions to remedy stress root causes by obtaining medical help or illness information (Folkman & Moskowitz, 2000). The emotional aspect of stress management corresponds to seek emotional help as well as perform stress-relieving actions (Lazarus & Folkman, 1984). People taking problem-focused approach to caregiving demonstrate more positive psychological effects than individuals who focus mostly on emotional coping mechanisms (Brotheridge et al., 2003).

When facing medical and emotional challenges of thalassemia parents apply both problem-focused and emotion-focused coping methods. Parents whose children have thalassemia obtain medical support from healthcare professionals combined with family members and religious or cultural practices from emotional support perspectives (Lauren & Guilbeault, 2018). Insufficient coping resources together with limited social networks create increased stress which worsens caregiver burden according to Lazarus & Folkman (1984) and Papastavrou et al. (2012).

Psychological Impact of Thalassemia

Thalassemia causes intensive psychological consequences which affect patients combined with severe effects on their family members. Children with thalassemia must deal with physical health conditions that include repeated blood transfusions combined with tiredness and dangerous medical issues (Victor et al., 1999). The health condition of thalassemia leads patients to develop mental health problems which include poor self-esteem and anxiety along with depression according to Koutelekos et al. (2013). The psychological conditions generated by thalassemia create patient lifestyle deterioration which results in individuals withdrawing socially and creating daily functional limitations (Ismail et al., 2013).

Caregivers must experience heightened psychological stress when caring for a thalassemia child due to concerning future health uncertainties and persistent medical requirements (Rajput et al., 2015). Caregivers commonly develop excessive emotional distress to the point it becomes depression and anxiety and also leads to burnout (Prasomsuk et al., 2007). The mental health condition of caregivers depends largely on their social network strength because higher levels of support minimize caregiver distress and boost mental health quality (Wang et al., 2017).

Hypotheses

Hypothesis 1: There would be a high level of caregiver burden among the parents of children with thalassemia.

Hypothesis 2: Psychological well-being will have a significant negative impact on the caregiver burden of parents of children with thalassemia.

Hypothesis 3: Coping strategies will likely lessen the caregiver burden of parents of children with thalassemia.

Methodology

A quantitative research design enabled study of caregiver burden as well as psychological health and coping approach among parents who care for children with thalassemia. The selection of 100 parents whose children carried a thalassemia diagnosis used convenient sampling as the study methodology. A high number of parents whose children have thalassemia diagnosis took part in the study from the hospitals within Pakistan's Khyber Pakhtunkhwa area which shows a notable occurrence of thalassemia. The data collection method relied on structured questionnaires which surveyed caregiver burden and coping mechanisms together with psychological well-being between parents of thalassemia patients.

The serving staff utilized the Zarit Burden Interview Scale to determine caregiver burden levels. The Zarit Burden Interview Scale stands as one of the most established tools to evaluate the total health effects of caregiving responsibilities on physical condition and emotional and social areas. The assessment of coping strategies depended on the Jalowiec Coping Scale A and Jalowiec Coping Scale B. These measurement tools evaluate coping strategies that embrace both dealing directly with problems and dealing emotionally with challenges related to caregiving stress. Participants responded to the Warwick-Edinburgh Mental Well-Being Scale (WEMWBS) for measuring their psychological well-being which assessed emotional responses as well as mental cognitive states.

The research data from these scales required descriptive statistical procedures for frequency and percentage analysis while correlation methods assessed relationships between caregiver burden and coping mechanisms and psychological emotional state. The research sought to discover important elements affecting caregiver burden together with how coping methods help reduce such burden. The relevant ethical committees approved the research while all participants received informed consent through which they obtained confidentiality and free will for their participation in the study.

Results

The analysis began with descriptive statistics to examine the basic characteristics of the sample and the variables of interest. The participants in this study were 100 parents of children with thalassemia, of which 60% were mothers and 40% were fathers. The average age of the participants was 35 years (SD = 6.2). The demographic characteristics of the participants are summarized in Table 1.

Table 1: Demographic Characteristics of the Participants

Demographic Variable	Frequency (n)	Percentage (%)
Gender		
Female	60	60%
Male	40	40%
Age Group		
18-30	30	30%
31-40	50	50%
41+	20	20%
Marital Status		
Married	90	90%
Single	10	10%

Note: The table shows the distribution of participants by gender, age group, and marital status.

The caregiver burden was measured using the Zarit Burden Interview Scale, with higher scores indicating greater caregiver burden. The mean score for caregiver burden was found to be 38.7 (SD = 8.5), suggesting a moderate level of burden among the participants. This result is summarized in Table 2.

Table 2: Descriptive Statistics for Caregiver Burden

Variable	Mean	Standard Deviation
Caregiver Burden (Zarit)	38.7	8.5

Note: The table shows the mean and standard deviation for caregiver burden as measured by the Zarit Burden Interview Scale.

Regarding coping strategies, the analysis revealed that problem-focused coping strategies were employed more frequently than emotion-focused strategies. The mean score for problem-focused coping (Jalowiec Coping Scale A) was 25.4 (SD = 6.2), while the mean score for emotion-focused coping (Jalowiec Coping Scale B) was 18.9 (SD = 5.4). This is summarized in Table 3.

Table 3: Descriptive Statistics for Coping Strategies

Coping Strategy Type	Mean	Standard Deviation
Problem-Focused Coping (A)	25.4	6.2
Emotion-Focused Coping (B)	18.9	5.4

Note: The table presents the mean and standard deviation for problem-focused and emotion-focused coping strategies.

A Pearson correlation analysis was conducted to explore the relationships between caregiver burden, coping strategies, and psychological well-being. The results revealed a significant negative correlation between caregiver burden and psychological well-being ($r = -0.65$, $p < 0.01$), indicating that higher caregiver burden was associated with poorer psychological well-being. Additionally, a significant negative correlation was found between emotion-focused coping and psychological well-being (r = -0.48, p < 0.01), suggesting that caregivers who relied more on emotion-focused strategies experienced lower psychological well-being.

Table 4: Correlation Between Caregiver Burden, Coping Strategies, and Psychological Well-Being

Variable	Caregiver Burden	Problem-Focused Coping	Emotion-Focused Coping	Psychological Well-Being
Caregiver Burden	-	-0.32*	-0.51**	-0.65**
Problem-Focused Coping	-0.32*	-	-	0.21
Emotion-Focused Coping	-0.51**	-	-	-0.48**
Psychological Well-Being	-0.65**	0.21	-0.48**	-

*Note: **p < 0.01, p < 0.05. The table presents correlations between the primary study variables: caregiver burden, coping strategies, and psychological well-being.*

A multiple regression analysis was conducted to examine whether coping strategies (problem-focused and emotion-focused) and caregiver burden predicted psychological well-being. The results indicated that caregiver burden and emotion-focused coping were significant predictors of psychological well-being (β = -0.60, p < 0.01; β = -0.45, p < 0.01, respectively), explaining 52% of the variance in psychological well-being. The regression model is summarized in Table 5.

Table 5: Regression Analysis: Predictors of Psychological Well-Being

Predictor Variable	β	Standard Error	T	p-value
Caregiver Burden	-0.60	0.10	-6.00	< 0.01
Emotion-Focused Coping	-0.45	0.08	-5.63	< 0.01
Problem-Focused Coping	0.12	0.09	1.33	0.19

*Note: **p < 0.01. The table presents the results of the multiple regression analysis, showing that caregiver burden and emotion-focused coping significantly predict psychological well-being.*

Discussion

This research investigation proves essential by revealing vital knowledge about the mental health state of adults who manage children with thalassemia and their handling methods alongside the associated care responsibilities. The study confirmed the existence of a significant negative connection between caregiver burden and psychological well-being (r = -0.65, p < 0.01) because caregiver burdens directly lead to decreased psychological welfare in caregivers. Studies on caregiver burden in families affected by chronic childhood diseases like cancer and diabetes validate the present research by showing that higher caregiver burdens produce poor mental health results (Kovacs, 1985; Gillis, 1993). Studies on thalassemic children caregivers (Rajput et al., 2015) parallel the research findings demonstrating that caregiver burden leads to substantial mental problems for parents while they support their children continuously.

Coping strategies demonstrate a vital role in reducing the negative effects which caregiver burden creates on caregivers. Research shows parental use of emotion-focused coping strategies results in a negative effect on their psychological well-being statistics with a correlation rating of -0.48 at the $p < 0.01$ level of significance. Emotion-focused coping has proven less effective than problem-focused coping at reducing stress as Lazarus and Folkman (1984) reported in their work. The use of emotion-focused stress reduction techniques which include seeking emotional support or practicing avoidance does not resolve stress factors and instead permits emotional tension to build up gradually (Folkman & Moskowitz, 2004). The educational aspect of problem-focused coping revealed itself through a modest positive relationship to psychological well-being ($r = 0.21$) since parents who worked on resolving their caregiving challenges achieved stronger mental wellness outcomes.

The results from regression analysis demonstrated that psychological well-being of caregivers was determined by 52% by the combination of caregiver burden and emotion-focused coping mechanisms. The high levels of importance for caregiver burden treatment demonstrate why better coping strategies should be provided to caregivers. Strategies which focus on emotional coping require intervention because they show potential to enhance caregivers' mental well-being through support groups and therapeutic approaches. Healthcare providers along with counselors must develop interventions by integrating social support frameworks with problem-solving methods as recommended in Wang et al. (2017).

The research adds to understanding how care for children with thalassemia affects caregivers emotionally by demonstrating the necessity for complete caregiver support programs. Research should track caregiver burden evolution in time along with studying possible tools such as trained care programs and support groups and relaxation techniques for reducing their burden. Qualitative research designs would uncover detailed insights about caregiver life experiences thus contributing to the development of stronger support systems for them.

Limitations

The significant findings presented in this research benefit from useful data but the study contains specific restrictions. The research design that uses cross-sectional analysis prevents researchers from establishing valid connections between caregiver burden and mental health status of caregivers. It would be beneficial to study caregivers implementing longitudinal research techniques because these methods help track the evolution of both their psychological state and their caregiver duties. The research used participants from a certain territory which hinders broad applicability of obtained results to all demographic groups. Further research must use samples consisting of different population groups found across various geographic areas to strengthen the general applicability of obtained findings.

Conclusion

The research evidence demonstrates that parental caregivers of children with thalassemia deal with substantial psychological weight coupled with inadequate adaptive responses. The research indicates that caring responsibilities produce adverse health consequences for parents and emotional coping practices lead to worse mental health results. Further research should develop specific interventions to help caregivers manage emotional needs together with practical requirements because it directly impacts their mental health. The improvement of parental coping mechanisms and lower levels of caregiver burden will create better life quality for parents alongside their children who have thalassemia.

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