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# Perceived Physical, Emotional and Monetary Burden among Caregivers of Thalassemia Patients: An Evidence-based Study from District Gujrat, Pakistan

Arooj Sikandar [1] Afzaal Afzal [2] Maryam Khalid [3] Marwa Nayab [4]

**Abstract:** *Thalassemia is among the most challenging hereditary blood disorders with no permanent cure. The patients of thalassemia have to face multidimensional complications that may lead to physical, emotional, social, and monetary burdens, among others, that negatively affect the patients, their families, and especially the caregivers. The caregivers feel the burden owing to the long-standing character of the diseases and the struggling process for curing patients, and the caregivers have to face numerous burdens that lead them towards anxiety, depression, social withdrawal, aggression, poor relationships, lower productivity, and many others. The prime objective of this study is to understand the physical, emotional, and monetary burdens faced by caregivers, and primary data for this quantitative study were collected from caregivers of thalassemia patients of district Gujrat. Researchers applied the purposive sampling technique and a structured questionnaire to approach the study participants. The findings highlighted that the caregivers of thalassemia patients face a large number of physical (continued attachment, tiredness, isolation, lower productivity), emotional (aggression, depression, fear of losing a loved one life), and monetary (visiting health centers, arranging blood donors, travel and transportation, personal obligations) burdens that have significant impacts on their socio-economic, psychological and physical health.*

**Key Words:** Thalassemia, Genetic Blood Disorder, Caregivers, Physical Burden, Emotional Burden, Monitory Burden

## Introduction

Thalassemia is among the most challenging hereditary blood disorders with no permanent cure. The patients of thalassemia have to face multidimensional complications that may lead to physical, emotional, social, and monetary burdens, among others, that negatively affect the patients, their families, and especially the caregivers (Nargis et al., 2023). The caregivers feel the burden owing to the long-standing character of the diseases and the struggling process for curing patients, and the caregivers have to face numerous burdens that lead them towards anxiety, depression, social withdrawal, aggression, poor relationships, lower productivity, and many others. A disease like thalassemia has many complications that may lead to physical, cognitive, social, and monetary burdens that negatively affect the patients, their families, and especially the caregivers (Atiye et al., 2022).

Caregivers who are normally the parents often experience high emotional stress due to witnessing the physical and emotional pain endured by their child. They may struggle with managing their physical fatigue and emotional instability and have difficulty finding joy or pleasure in activities they used to spend their leisure time (Saqlain et al., 2022). Everyone has a different situation and faces different problems from each other, and their experiences with disease also vary from others. The monetary burden also

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[1] Associate Lecturer/Research Officer, Department of Sociology, University of Gujrat, Punjab, Pakistan. Email: arooj.sikandar@uog.edu.pk
[2] Community Development Officer, Housing Urban Development & Public Health Engineering Department, Punjab, Pakistan.
[3] Lecturer, Social Work, Higher Education Department, Punjab, Pakistan. Email: maryam.kp@yahoo.com
[4] BS Sociology, Department of Sociology, University of Gujrat, Punjab, Pakistan. Email: marwa.nayab56@gmail.com

- **Corresponding Author:** Afzaal Afzal (afzaal.afzal2010@gmail.com)
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affects their ability to think clearly and process information effectively. Continuous worry about their child's health can disrupt their daily routines and activities. Simple tasks such as household chaos, job, sleeping schedule, or maintaining a regular eating schedule may become challenging. Caregivers may experience a loss of interest, motivation, and satisfaction, leading to neglect of their personal well-being and responsibilities (Yousuf et al., 2022).

During the process of curing patients with thalassemia, the caregivers have to face a multidimensional burden that leads them towards lower productivity and distractions, among others (Ibrahim, 2021). Pressure increased among caregivers due to poor life expectancy, future complications fear, decreasing physical health, instability of emotional health, irritated rot, the burden of medication and arranging blood donors and visits to health care centers, among others (Biswas et al., 2022). Caring for a thalassemia patient is a complex process with numerous negative reactions faced by caregivers, such as personal, social, communal, and financial burdens that have subjective as well as objective dimensions. Subjective dimensions refer to the burden of caregiver knowledge, the experience of taking care, and behavioral and attitude aspects, while objective dimensions indicate the duration, level of effort, and patience to deal with the socio-economic situation (Ahmadi et al., 2020).

A caregiver's daily routine deeply affects the process of caregiving, reducing the quality of life, personal enjoyment, time spent with peers, and productive work as a common man. Furthermore, the most important aspects of caregivers' lives are the relationship and involvement with other family members, attending family gatherings, and traveling outside their homes. With the passage of time and lethargic workload, the quality of life and livelihood of caregivers are significantly affected, which creates stress and frustration, which leads those towards physical and emotional disorders badly (Subardhini et al., 2019). Numerous factors, such as individual health, duration of care, family income, level of social support, anxiety, and increase in economic and monetary burden, make things more complicated for caregivers (Tarım et al., 2022).

The caregivers encounter financial, physical, emotional, and monetary burdens and a lack of effective facilities for preventive and curing health. A large number of existing studies (Subardhini et al., 2019) indicated that the physical burden faced by caregivers impacted their growth, development, and well-being through different aspects such as frustration, helplessness, isolation, communal segregation and, above all, dissatisfaction with normal life (Nabavian et al., 2022). The caregivers of thalassemia patients, who are normally the mothers of children, always feel the fare of life and future of their child. They blame themselves for the conditions and occasionally feel dissatisfied with the improvement of health conditions and treatment process. Responsibilities from other family matters and taking care of their family indulge them physically as well as emotionally to perform their obligations (Ahmadian et al., 2022).

The situation is more alarming in developing countries like Pakistan, with more than half of its population living below the poverty line and meager access to basic life and health facilities. The issue of thalassemia is one of the important public health issues that affects almost 5 to 8 percent of newborns every year. There are about 5000 thalassemia patients reported every year in Pakistan, and the number is increasing day by day (Aziz et al., 2017). Furthermore, the families with thalassemia patients have to deal not only with the patient's diseases but also multidirectional social, psychological, and economic burdens, among others. Continued caregiving to patients, arranging blood donors on a regular basis, and visits to health care centers, fear and uncertainty significantly impacted the whole family, their quality of life, and livelihood (Atiye et al., 2022). Therefore, investigating the burden faced by caregivers of thalassemia patients needs special attention for better care, appropriate methods, and results, which not only reduce the caregiver burden but are also helpful for patients. In this regard, the researcher designed a study to understand the physical, emotional, and monetary burden faced by the caregivers of thalassemia patients.

## Objectives of the Study

- To examine the physical, emotional, and monetary burden among caregivers of thalassemia patients in District Gujrat.
- To investigate the impacts of a physical, emotional, and monetary burden on caregivers of thalassemia patient’s life.

## Research Methodology

To understand the existing situation and perceived physical, emotional, and monetary burden among caregivers of thalassemia patients, researchers applied quantitative research techniques. The research study was conducted in the district of Gujrat, Pakistan, and the primary data was collected through a purposive sampling technique from a selected population. The participants of this study were the caregivers of thalassemia patients living in district Gujrat. Researchers visited the thalassemia care institute of Gujrat city and had detailed meetings with the receptionist for patients and caregivers, visiting the institutes with their patients for fifteen days. The researcher also distributed the questionnaire to those students who have thalassemia patients at home and asked them to fill out the questionnaire from caregivers within three weeks after the completion of data collection. A total of 360 participants were approached for data collection purposes.

The collected data was edited and entered in the SPSS-22 for further advanced statistical analyses. The descriptive analyses showing frequencies and percentages and other descriptive statistics were generated. The independent and dependent variables were further recoded to develop indices. These indices were developed to check the relationship between independent and dependent variables and to carry out further statistical analysis.

## Conceptual Framework

The conceptual framework consisted of the explanations of study variables that have been included in the existing literature and also the researchers applied to measure the variables in this study.

## Physical Burdens Faced by the Caregivers

Physical burdens faced by the caregivers of thalassemia patients refer to the caregiver's restlessness and fatigue because of the improper sleep schedule and always feeling tired and inactive. The first statement asked to know the tiredness that the caregiver feels tired all the time. The next two dimensions are to know the trouble in sleeping. The researcher means that when a person is in a worrying situation, they do not properly sleep due to the negative thoughts, and their sleep is always restless. Further dimensions are added to ask about the caregiver’s physical strength in doing everyday activities as they did not feel enough energy to do work and felt mentally exhausted. The next two statements were asked to know about these worries and restless lead them toward depression or other mental health problems because when the person is unable to fulfill the body's energy properly, such as proper sleep and diet, then the body does not work properly and person have not physically and mentally strength to do the work.

Furthermore, the caregiver feels physical burdens due to the actual understanding and time limits of this rot. The unawareness of actual information regarding diseases and lack of social support by family members and relatives enhance the responsibility of giving. Economic burden, e.g., not having enough resources to deal with the expenses of treatment. Barriers to accessing health care services include long travel to the thalassemia center, blood arrangements, etc. Lack of knowledge and information includes not enough information about thalassemia and not being aware of the nature and treatment of the disease.

The feeling of uncertainty regarding future life and various other dimensions also includes those stressful and unforeseen events that make the caregivers upset, and sometimes they think it is unfair that other persons are sure about their future life, and this kind of uncertainty makes them unhappy and hopeless. Further dimensions are included to know that they feel fearful and worried about their child's life expectancy and whether they are hopeful for the recovery of their child.

## Emotional burden Faced by the Caregivers

The emotional burden faced by the caregivers was taken as the dependent variable, and the researcher measured the various emotional problems faced by the caregivers. This variable has been measured, such as loss of interest, feeling of hopelessness, feeling of uncertainty, fatigue, restlessness, and feeling of guilt and worthlessness. These burden challenges cause disturbance in caregivers' own lives. The important aspects that affect the caregiver’s mental health are stress, restlessness, mental strain, feelings of guilt, improper sleep, and always worries about the child's health.

Researchers considered other interrelated aspects of understanding the emotional support of family members to the caregivers in stressful situations. The patients and the caregivers can count on their family in every matter, which means they discuss their problems with family members and can rely on them in case of emergency or their family helps them regarding the caregiving responsibilities of the patient. The relative support regarding the disease and the sharing of their responsibilities with family and neighbors, or they may feel hesitation in meeting them. The ignorance and rude response from the relatives due to the blood demand significantly disturb the caregivers and the patient's family.

The researcher measured emotion-focused coping and tried to understand how the people emotionally cope with the situation. Different dimensions were to know about how they prefer to discuss their feeling with friends or family for mental peace so that they can feel mentally relaxed. The emotional strength from others or prefer to stay alone for a while and cry in loneliness. Furthermore, they get sympathy from others and avoid interacting with people. Also, they try to relate with people who have similar experiences, and sometimes, they feel so much emotional pain that they keep sitting in a corner for longer periods of time and thinking about their worries.

### Monitory burden faced by the caregivers

The monetary burden faced by the caregivers is the third indicator, which is measured to know about the feeling of pleasure while performing their daily life activities and then their feeling of interest in meeting other people. As the researcher mentioned in this study, people who are facing mental disturbance want to live alone rather than to meet others. The loss of interest in everything due to the worries of the child's health and the absence of focus means caregivers are unable to perform their tasks with complete focus because of the mental strain, and nothing makes them happy and active while performing their daily life activities.

Researchers focused on the feelings of guilt and worthlessness those caregivers face in their lives, and if they feel like they could not make any effort to prevent the disease or if they could have gone through medical tests before marriage, they could have prevented this disease. They feel guilt that they did not go through a complete medical test before making the child's decision and also blame themselves regarding their child's condition. They feel worthless and wish that they could do some miracle to get their child rid of the disease.

By the feeling of hopelessness, the researcher means the reasons for the loss of hope of caregivers. They feel worried about their child's health, hope for their child's recovery, and always worry about their condition and the chances of survival of their children. Because of the hopelessness, caregivers feel less chance of survival of their child, and sometimes they think that giving up would be easier for them. Hope for the future life of their children, and how hopeful the families are for the healthy and longer life expectancy of their child in the future.

Because of the Lack of information and knowledge, the caregivers did not have adequate information and experience about the thalassemia disease and faced many challenges in accessing health care services. There is a lack of information about the disease, information from social media or other sources, and awareness about the nature and treatment of the disease, and they know or do not know where to seek information and professional help regarding the treatment.

## Results and Major Findings

### Descriptive Analysis

The prime objective of this study was to understand the existing situation and perceived physical, cognitive, and monetary burden among caregivers of thalassemia patients. Researchers intended to examine the relationship of independent factors with the dependent variable. For coherent discussion and background understanding of participant circumstances, the following tables presented the demographic distribution of participants' characteristics.

**Table 1**

*Demographic distribution of participants' characteristic*

| Characteristics | Aspects | Percentages | Number |
|---|---|---|---|
| Locality of participants | Urban | 39.1 | 102 |
| | Rural | 60.5 | 158 |
| | **Total** | **100.0** | **360** |
| Participants gender | Male | 36.8 | 96 |
| | Female | 62.8 | 164 |
| | **Total** | **100.0** | **360** |
| Distribution of Age (in years) | 27-31 | 10.7 | 25 |
| | 32-36 | 19.6 | 51 |
| | 37-41 | 24.1 | 70 |
| | 42-46 | 20.9 | 50 |
| | 47-51 | 13.1 | 45 |
| | 52-56 | 7.7 | 10 |
| | 57-61 | 3.1 | 8 |
| | 62-66 | 4 | 1 |
| | **Total** | **100.0** | **360** |

Table 1 presents the demographic results and indicates that most of the study participants, 60.5% of whom belong to the rural area of district Gujrat, and 39.1% of participants live in urban localities. Researchers collected primary information from 36.8% of male and 62.8% of female caregivers of thalassemia patients, and among them, most of the caregivers 24.1% fell in the age bracket of 37-41years, 20.9% were between 42-46 years and 19.6% were 32-36 years. There are 4% participants who were taking care of thalassemia patients even at 62 or more years of age.

**Table 2**

*Demographic distribution of participants' characteristic*

| Characteristics | Aspects | Percentages | Number |
|---|---|---|---|
| Qualification | 0-5 | 53.3 | 139 |
| | 6-10 | 23.4 | 61 |
| | 11-16 | 23 | 60 |
| | **Total** | **100.0** | **360** |
| Family System | Nuclear | 74.7 | 195 |
| | Joint | 24.9 | 65 |
| | **Total** | **100.0** | **360** |
| Participants occupation | Government job | 7.3 | 15 |
| | Agriculture | 28.7 | 73 |
| | Business | 22.2 | 50 |
| | Private job | 13.0 | 40 |
| | Unemployed | .8 | 2 |
| | Labor | 27.2 | 80 |
| | **Total** | **100.0** | **360** |
| Per month family Income (PKR) | Up to 20000 | 12.2 | 32 |
| | 20001-30000 | | |
| | 30001-40000 | 16.5 | 43 |
| | 40001-50000 | 24.1 | 63 |
| | 50001-60000 | 44.4 | 116 |
| | 60001-70000 | 2.2 | 6 |
| | **Total** | **100.0** | **360** |

Table 2 also indicates the demographic distribution of participants, as only a few number 23% of participants have an education level higher than matriculation. Of the maximum number of participants, 74.7% are living in the nuclear family system, and out of the total, 28.7 participants are related to agriculture, 28.7%. The findings indicated that a huge proportion of the population, 44.4%, has a monthly income of 50001-60000 rupees.

Table 3

*Perceived physical burden faced by the caregivers of thalassemia patients*

| S No. | Physical Burden | SA %(f) | A %(f) | SDA %(f) | DA %(f) |
|---|---|---|---|---|---|
| 1 | You feel tired all the time. | 77.4 (202) | 21.1(55) | .4 (1) | .8 (2) |
| 2 | You have trouble sleeping due to worry. | 68.6 (179) | 31.0(81) | 0 | 0 |
| 3 | Your sleep is always restless. | 59.0 (154) | 39.8(104) | .4 (1) | .4 (1) |
| 4 | You did not feel enough energy for everyday life. | 63.0 (166) | 36.0 (94) | 0 | 0 |
| 5 | You feel mentally exhausted. | 61.7 (167) | 36.4 (95) | 1.1 (3) | 1 (1) |
| 6 | You feel laziness performing routine activities. | 54.4 (142) | 41.4(108) | 1.5 (4) | 2.3 (6) |
| 7 | Continuous restlessness leads you toward depression. | 47.5 (124) | 33.0 (86) | 3.8(10) | 15.3 (40) |

According to the results presented in Table 3, out of a total, 98% of caregivers feel tired all the time, and they do not feel enough energy for everyday life. 99% of caregivers feel tired and have low energy in everyday life, and 68.6% strongly agree that they face trouble sleeping due to worry and that their sleep is always restless. The results show that the majority of caregivers face restless sleep due to the worry of the child, and 96.7% always feel mental disturbance. When a person feels tired and has low energy, he/she is unable to perform his/her activities with complete focus and attention. Similarly, the majority of caregivers feel laziness during their routine activities, and about 78% think that this restlessness and worry leads them toward depression. All the data in this table indicate that the majority of parents feel tired and restless, which makes them unable to perform their activities actively.

Table 4

*Perceived emotional burden faced by the caregivers of thalassemia patients*

| S No. | Emotional Burden | SA %(f) | A %(f) | SDA %(f) | DA %(f) |
|---|---|---|---|---|---|
| 1 | You do not have pleasure in your daily life. | 81.6 (213) | 18.0 (47) | 0 | 0 |
| 2 | You don’t like to meet people. | 46.7 (122) | 36.0 (94) | 4.6 (12) | 12.3 (32) |
| 3 | You have lost interest in everything. | 38.3 (100) | 37.9 (99) | 3.1 (8) | 20.3 (53) |
| 4 | You are unable to perform your task properly. | 52.5 (137) | 44.4 116) | 1.9 (5) | 0.8 (2) |
| 5 | You feel worried about your child’s health | 37.9 (99) | 35.6 (93) | 8.0 (21) | 18.0 (47) |
| 6 | You feel giving up would be easier | 62.1 (162) | 36.4 (95) | 0.4 (1) | 0.8 (2) |
| 7 | You believe that things will improve. | 0.8 (2) | 1.5 (4) | 6.5 (17) | 90.8(237) |
| 8 | You feel tired all the time. | 77.4 (202) | 21.1 (55) | 0.4 (1) | 0.8 (2) |
| 9 | You feel mentally exhausted. | 61.7 (167) | 36.4 (95) | 1.1 (3) | 1 (1) |
| 10 | You feel like I am not a good parent. | 10.7 (28) | 23.4 (61) | 22.6(59) | 42.9(112) |
| 11 | Continuous restlessness creates depression. | 47.5 (124) | 33.0 (86) | 3.8 (10) | 15.3 (40) |
| 12 | You blame yourself for the child's condition. | 13.0 (34) | 26.4 (69) | 14.6(38) | 45.6(119) |

Table 4 shows that people lose their interest because of their child's health. As we can see, 81.6 of the caregivers 81.6 % do not feel pleasure in their daily life activities. At the same time, 46.7% of caregivers do not like to meet other people and gradually lose interest in everything, which is higher than the disagree percent 23%. Caregivers are unable to perform their tasks properly; however, 48% of parents did not agree with the statement. Similarly, 76% did not feel happiness. Mostly, 62.1% strongly agreed with the situation, and 0.8% people disagreed with it. This means that the majority of the population cannot completely focus on their work. All the data shows that the majority of parents do not feel pleasure and satisfaction while performing their daily life tasks and give positive responses to questions.

### Table 5

*Perceived monetary burden faced by the caregivers of thalassemia patients*

| S No. | Monetary Burden | SA %(f) | A %(f) | SDA %(f) | DA %(f) |
|---|---|---|---|---|---|
| 1 | You prefer to use self-medication at home. | 22.2(58) | 28.4(74) | 16.5(43) | 32.6(85) |
| 2 | You prefer to consult with professionals | 78.9(206) | 19.2(50) | 0.8(2) | 0.8(2) |
| 3 | You use herbal medicine to cure the disease. | 22.2(58) | 28.4(74) | 16.5(43) | 32.6(85) |
| 4 | You use different techniques daily for recovery. | 57.9(151) | 35.2(92) | 3.4(9) | 3.1(8) |
| 5 | Trying physical exercises for treatment. | 74.7(195) | 24.9(65) | 0.0 | 0.0 |
| 6 | You ask other people about their experience | 76.6(200) | 22.2(58) | 0.4(1) | 0.4(1) |
| 7 | Seek information for better coping | 63.2(165) | 33.7(88) | 1.1(3) | 1.5(4) |
| 8 | You keep yourself updated about the latest facility development | 66.7(174) | 31.8(83) | .00 | 1.1(3) |
| 9 | You frequently visit the thalassemia center for cure and treatment | 69.0(180) | 28.0(73) | 1.1(3) | 0.8(2) |

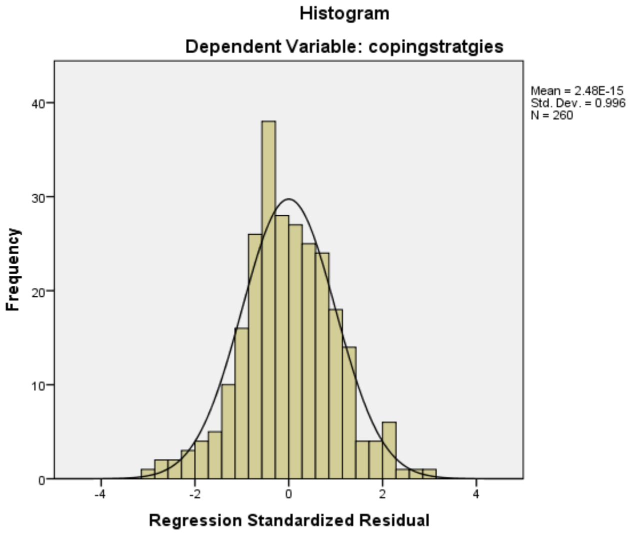
Table 5 indicates the monetary burden faced by the caregivers, and results indicated that most of the time, caregivers prefer self-medication at home, and 98% of parents prefer to consult a professional doctor for treatment. To cure the disease, patients and caregivers use different sources to search for methods for recovery, and 93% of parents agree with it. The results indicated that the majority of caregivers use different sources to search methods. Out of a total, 97% of caregivers keep themselves updated about the latest developments regarding the cure and prevention of thalassemia. All the results indicate that the majority of the parents use allopathic medicine instead of self-medication and use different sources to search for the method of treatment.

## Normality Analyses

The normality analyses were used by the researchers to determine the normal distribution of collected study data. The Shapiro-Wilk test and Kolmogorov-Smirnov test are frequently applied in social science to understand the nature and trends in data. The following histogram figure is the graphical representation of data distribution, and it is useful for understanding the shape of the data distribution. The graph is bell-shaped, indicating the data is normally distributed.

### Figure 1

*Histogram of normality test*



## Correlation Analysis

To measure the relationship among two and more than two variables, researchers applied correlation analysis. The test of correlation supports understanding the direction and strengths of associations among considered variables. In this study, the researcher intended to understand the associations between dependent and independent variables. For this purpose, Pearson correlation analysis and the findings are presented in Table 6.

Table 6

*Correlation analysis findings*

| | | Physical Burden | Cognitive Burden | Monetary Burden |
|---|---|---|---|---|
| Physical Burden | Pearson Correlation | 1 | .372** | .420** |
| | Sig. (2-tailed) | | .000 | .000 |
| | N | 260 | 260 | 260 |
| Emotional Burden | Pearson Correlation | .372** | 1 | .395** |
| | Sig. (2-tailed) | .000 | | .000 |
| | N | 260 | 260 | 260 |
| Monetary Burden | Pearson Correlation | .420** | .395** | 1 |
| | Sig. (2-tailed) | .000 | .000 | |
| | N | 260 | 260 | 260 |

**. Significant at the 0.01 level (2-tailed).

Table 6 shows the values of correlation that indicate the strength and direction of association among independent and dependent study variables. The correlation indicates significant and positive at the level of 0.01 association and at the 0.05 connections between the considered study variables. The results presented in Table no 6 indicated that physical burden and emotional burden have a positive correlation, i.e., .372. Similarly, the relation between physical burden and monetary burden also has a positive and strong correlation, i.e., .420, and the correlation between emotional burden and monetary burden also has a strong correlation.

## Analyses of Variance

The findings from the variance analysis present the average comparison of considered study variables and highlight the level of impact on each other. The assumption from the analysis is that the entire considered burden measure in the study, such as physical, emotional, and monetary burdens faced by caregivers, have significant impacts on caregivers' daily lives.

Table 7

*Findings of ANOVA*

| Model | | Sum of Squares | Df | Mean Square | F | Sig. |
|---|---|---|---|---|---|---|
| 1 | Regression | 2761.891 | 3 | 1652.762 | 44.827 | .000[b] |
| | Residual | 8272.786 | 321 | 29.637 | | |
| | **Total** | **10848.596** | **324** | | | |

The results from Table 7 indicated that the sum of squares measured in this study is less than the residual sum of squares. This shows that the poor variation exited in the dependent variable of the study and the significant values observed in the results of the F-test and the P value that leads to the rejection of the test hypothesis that unites all considered independent study variables do not affect the dependent variables.

Table 8

*Coefficients analysis findings*

| Model | | Un-standardized Coefficients | | Standardized Coefficients | T | Sig. |
|---|---|---|---|---|---|---|
| | | B | Std. Error | Beta | | |
| 1 | (Constant) | 81 .921 | 4.667 | | 09.726 | .000 |
| | Physical burden | .342 | .026 | .425 | 4.621 | .000 |
| | Cognitive burden | .635 | .0776 | .662 | 3.832 | .000 |

a. Dependent Variable: coping strategies

Table 8 represents the values of coefficients that predict the strength of the relationship between the independent and dependent variables. Coefficients have shown the importance of independent variables in making regression models. Physical burden and emotional burdens influence coping strategies. This influence is significant because the p-value of the predictor is less than 0.05.

## Discussion and Conclusion

The present study examined the relationship between perceived physical, emotional, and monetary burdens among caregivers of thalassemia patients. Descriptive analysis and inferential statistics were applied to measure the objectives of the studies. Kolmogorov - Smirnov and Shapiro-Wilk test was used to check the normality of data. Pearson correlation test was used to check the relationship between dependent and independent variables, and it also helped to examine caregivers' perceptions of adopting different coping strategies for reducing psychological and social stress.

The finding suggested that caregivers often feel hopelessness regarding the healthy life of their child. They were not sure about the full recovery of their child, which made them hopeless and mentally distressed. This finding is also supported by the work of caregivers who experienced various types of physical burden and cognitive burdens, such as anxiety, fear of losing life, denial, worry, hopelessness, frustration, and unhappiness. This finding is also supported by the work of caregivers of children with chronic pain who reported high levels of stress, anxiety, depression, and impaired emotional function.

Another finding of the present study suggested that the caregivers feel uncertainty about the future life of a child, and they feel fear about the life expectancy of their child. As a result of this uncertainty, they remain unhappy and hopeless. This finding was supported by caregivers who felt that they had lost their healthy children and were afraid of losing them completely through sudden death. The fear of sudden death was associated with the feeling of hopelessness, as they felt that there was no hope for their children’s cure. Researchers also examined that sometimes parents often feel guilt and worthlessness and think they did not make any effort for the prevention of disease. This finding is supported by the work that parents of children with thalassemia disease felt guilt, frustration, and worthlessness, and this feeling increased their distress and worry about their child’s current health status and their future.

Researchers examined that caregivers use different coping strategies to cope with stressful situations, which means they discuss their feelings with friends and family to seek emotional strength from others, or sometimes they keep crying in loneliness. Fathers read, get information from different sources, and look for the best doctor in town for treatment. On the other side, mothers seem to be more emotional and spiritual. For example, they were crying, praying, and reciting the Holy Quran.

## Recommendations

This research is conducted in only one thalassemia organization. Future research can be conducted on different or more organizations to explore the other hidden challenges faced by caregivers. Future research can also be conducted on psycho-education that explores comprehensive information about thalassemia, its treatment, and its impact on patients and gives unique strategies for managing the psychological and social challenges associated with caregivers. Further, studies can be conducted on the importance of self-care of caregivers that encourage the caregivers to engage in activities that give them relaxation and encourage adaptive coping strategies that educate and make the caregivers aware of various coping strategies such as problem-solving skills and positive thinking. Future research can also be conducted to explore the impact of thalassemia on siblings or to explore the experiences of nurses dealing with thalassemia major patients.

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