



An Investigation of the Role of Stress in affecting the Cognitive functioning and Psychological Adjustment of Caregivers of Children with Thalassemia

ISSN (Online): 3007-1038

Pages: 132-137

DOI: 10.62997/rl.2025.42076

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Abstract: To examine the role of stress in affecting the cognitive functioning and psychological adjustment of caregivers of children with thalassemia. It was a Cross-sectional observational study. The stress, cognitive functioning, and psychological adjustment were measured by using the Perceived Stress Scale, the Montreal Cognitive Assessment, and the Scale of Adjustment for Adults, respectively. Other necessary information was asked on the demographic sheet. The data of 200 caregivers of the children with thalassemia was confirmed by using analysis of Structural Equation Modeling, and the model fit was confirmed with the p-value of .004. It established that stress predicts the cognitive functioning and psychological adjustment of caregivers of the children with Thalassemia whereas inspecting the relationship among the variables individually, the stress predicts cognitive functioning with the regression estimates of -0.216 with a p-value, .000 which specifies that if stress increases by 1 unit the cognitive functioning lower down to 0.216. While the role of stress in affecting psychological adjustment had regression estimates of 2.276, which implies that if stress increases by 1 unit, the increase in psychological adjustment problems is by 2.276 (p-value, .000). There was a role of stress in affecting the cognitive functioning and psychological adjustment of caregivers of the children with thalassemia.

Key Words: Caregivers, Children, Cognitive Functioning, Psychological Adjustment, Stress, Thalassemia

Introduction

Thalassemia is a hereditary genetic disorder that has the tendency to lower or inactivate the production of globin chains. It can be in 2 types like α -thalassemia, in which no chains are produced, and β -thalassemia, in which some chains are produced at a reduced level (ScienceDirect, 2020). It has been confirmed by experts that approximately 5000 Pakistani children are diagnosed with this problem every year (The Express Tribune, 2020).

Normally, people emphasize the patient's rational stability and do not focus on the mental health of the caregivers. The caregivers of thalassemia may also be affected psychologically in managing the problem. Among other things, the caregivers encounter stress. Stress was initially defined by Selye as a body response to any demand for change. Stress is not only the alteration in a body response, but more precisely, a change in psychological, somatic, expressive strain or tension. Whether it is a good or bad situation, if an uncontrollable situation occurred, then it caused stress (Selye, 1975). There are two types of stress: the first type is acute stress, which describes the rapid reaction of your body to different challenges. It involves a fight-or-flight action that is sudden and fixed quickly. If the acute stress is not resolved and continues for long periods of time, then it becomes chronic stress. This type of stress is constant and does not settle down easily (Legg, 2020). Research in Pakistan has confirmed the view that the caregivers of thalassemia encounter perceived stress (Hisam et al., 2018; Mallya & Fiocco, 2018). The stress in caregivers may alter their cognitive and psychological adjustment.

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Citation: Naz, I., Mobeen, F., & Ansar, A. (2025). An Investigation of the Role of Stress in affecting the Cognitive functioning and Psychological Adjustment of Caregivers of Children with Thalassemia. *Regional Lens*, 4(2), 132-137. <https://doi.org/10.62997/rl.2025.42076>

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Cognitive dysfunction may be the most obvious problem encountered by the caregivers of thalassemia. The important cognitive abilities may include language, concentration, perception, recall, and executive functioning (Wallin et al., 2018). The previous research has established the fact that stress alters cognitive reactions, as a study confirmed that caregivers showed a decline in cognitive functioning and 12% of the caregivers had a worse cognitive ability compared to the patients (Kurita et al., 2018). The caregivers may have problems with cognitive flexibility, unable to generate or learn more words (Mallya & Fiocco, 2018).

In addition, there is the possibility that stress can have an effect on the psychological adjustment of people who are responsible for providing care to patients who have thalassemia disorders. According to Searle and Ward (1990), adjustment may be seen as a behavioral process that seeks to maintain a balance as a result of the numerous demands and challenges that humans face in order to adjust to their environment. This is because individuals are forced to adjust to their environment in order to survive. The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) contains the criteria for adjustment disorder, which are the most effective way to comprehend psychological adjustment. These criteria are contained in the DSM-5. In an accommodating manner, in less than three months after the stressor was encountered, the disease offered an explanation for the emotional and behavioral abnormalities that were brought on by a number of different stressors. It is also essential that it be accompanied by clinical deterioration in order to be considered complete. Additionally, the symptoms that are symptomatic of the condition include, but are not limited to, behavioral concerns, depressed symptoms, anxious symptoms, or a combination of both, as well as a combination of emotions and conduct issues (American Psychiatric Association, 2022). In-person manifestations of behavioral difficulties, anxiety, and depression were seen in the individuals who were specified as having adjustment challenges. Seventy-four percent of caregivers exhibited symptoms of depression, according to the findings of a study carried out by Dirikkan et al. (2018). Furthermore, eighty-four percent of caregivers indicated concern regarding the prognosis and the adjustment to the treatment.

In spite of the fact that there is a lack of awareness surrounding the issue, the research that was conducted in 2019 by Ibrahim and colleagues found that thalassemia is considered to be a major genetic ailment in Pakistan. As a consequence of this circumstance, the weight of the disorder is a substantial source of stress for the individuals who are responsible for the care of the individual who is affected by it. Especially when these aspects are taken into consideration, the number of studies that have been undertaken on caregivers of thalassemia patients is exceedingly limited. On the other hand, despite the fact that the functions of caregivers are of the utmost significance for patients, they are often overlooked. Therefore, the objective of the current study was to evaluate the influence that stress has on the cognitive functioning and psychological adjustment of caregivers who are responsible for children who have thalassemia. Specifically, the research aimed to investigate the impact that stress has on mental health.

Methodology

An observational cross-sectional study was conducted at the Department of Psychology, University of Gujrat. The data for the study were gathered from the caregivers of children with thalassemia on the inclusion criteria of age above 19 years from the hospitals and community of Islamabad and Gujrat. Furthermore, the diagnosis of thalassemia must be made within 6 months to 2 years. The caregivers with any physical and psychological disorder must be excluded from the study, along with participants below the age of 19 years. The purposive non-probability sampling technique was used to sample 200 caregivers from Islamabad and Gujrat hospitals and the community. The sample characteristics of the purposive sampling technique were on the caregivers of thalassemia, the duration of diagnosis must be between 6 months and two years, and the age must be above 19 years.

Perceived Stress Scale Urdu Version (Cohen et al., 1983; Mariam et al., 2020), Montreal Cognitive Assessment Urdu version (Habib et al., 2010), and Scale of Adjustment Problems for Adults Urdu Version (Naz et al., 2018) were the instruments that were utilized in order to measure the constructs of stress, cognitive functioning, and psychological adjustment. For the purpose of determining the characteristics of the participants, a detailed demographic questionnaire

was also utilized. First and foremost, the researcher went to the authors and asked for permission to utilize their tools for the purpose of research. Following this, the formal permission letters for the data collection were received from the department head, and these permission letters were then submitted to the administration office of the hospitals in order to obtain authorization. For the purpose of data collecting, the researcher went to the hospitals herself and interacted with the caregivers of the patients on an individual basis. By conducting face-to-face interviews with the caregivers, we were able to obtain their informed consent and then administer the scale battery to them. In the beginning stages of the research project, the respondents were given instructions in addition to the fundamental and essential information that could be found in relation to the study. Of the utmost importance, they were free to withdraw from the study at any point in time without incurring any penalties. The individuals who participated in the survey were enticed to see the scale statements in a rational manner and provide a genuine response that accurately conveyed their emotions. The replies were recorded on the questionnaire. Each and every one of the respondents' ethical reasons was preserved in their entirety.

Data Analysis

The data analysis was done by using Structural Equation Modeling (SEM) and descriptive statistics on Analysis of Moment Structures (AMOS) (version 21) and Statistical Package for Social Sciences (SPSS) (version 22) for Windows.

Results

The 200 caregivers of children with thalassemia were studied in the research. Their mean age was 35.53, with a range of 19 to 65.

Table 1

Model Fit Summary of Confirmatory Factor Analysis (N=200)

P Value	Chi-Square/df	Goodness of Fit Index	Adjusted Goodness of Fit Index	Comparative Fit Index	Root Mean Square Error of Approximation
.004	1.67	.953	.941	.907	.058

Table 1 indicates the p-value of .004 in the model fit summary, and if the p-value is less than .05, it means that the model is significant. It confirmed that there was a role of stress in affecting the cognitive functioning and psychological adjustment of caregivers of children with thalassemia. Whereas the model fit indices were also in the literature specific cut-offs as the chi-square/df (1.67), Goodness of Fit Index (GFI: .953); Adjusted Goodness of Fit Index (AGFI: .941); Comparative Fit Index (CFI: .941); and Root Mean Square Error of Approximation (RMSEA: .058).

Moreover, to confirm the results, the regression weight estimates were also inspected. These estimates specify the amount of change in the dependent variable due to the independent variables.

Table 2

Regression Estimates of Stress, Psychological Adjustment, and Cognitive Functioning in Caregivers (N=200)

Factors	Estimate	P
Adjustment<---Stress	2.276	.000
Cognitive functioning <---Stress	-.216	.000

Table II shows that the stress predicts psychological adjustment regression estimate was 2.276 with a p-value of .000. It confirms the fact that if stress goes up by 1, psychological adjustment problems go up by 2.276. This specifies that stress boosts adjustment problems in caregivers of children with thalassemia. Further, if stress goes up by 1, the cognitive functioning goes down by 0.216 with a p-value, .000 so the prediction is significant.

Discussion

The authorities have insufficiently addressed the issue of thalassemia, despite its large contribution to the mortality rate among infants under five years old (Angastiniotis & Lobitz, 2019). Thalassemia is considered the most severe and documented genetic disorder in humans. This is a significant public health issue. The load of thalassemia adversely affects the caretakers, necessitating an investigation into their state. This study, conducted on caregivers of children with thalassemia, seeks to examine the role of stress in affecting cognitive functioning and psychological adjustment. The link was determined using structural equation modeling, which indicated a model fit summary with a p-value of .004, lower than .05. This study indicates that the stress experienced by caregivers of thalassemia patients is a significant predictor of their cognitive functioning and psychological adjustment. Furthermore, the other chi-square/df indices were 1.67, and the research revealed that the value could not exceed 3 for a model to be deemed appropriate (Byrne, 2006). Hooper et al. (2008) reported that the Goodness of Fit Index (GFI) and the Adjusted Goodness of Fit Index (AGFI) were .953 and .941, respectively, with the literature suggesting that the threshold is above .90. Hu and Bentler (1999) assert that a Comparative Fit Index (CFI) value over .90 is deemed satisfactory. Browne and Cudeck (1993) reported that the Root Mean Square Error of Approximation (RMSEA) in their study was .058. The literature on RMSEA indicates that the value should be below 0.08. The findings indicated that stress significantly affects the cognitive performance and psychological adjustment of individuals caring for children with thalassemia.

Furthermore, structural equation modeling provides regression estimates that elucidate the individual relationships among the variables. The regression estimate of the link between stress and cognitive functioning was -.216, with a p-value of .000. A one-point increase in stress was observed to accumulate, according to the research. A decline in cognitive functioning is noted as number 216. Research indicates that stress is a strong predictor of cognitive function in caregivers (Lathan et al., 2016; Kurita et al., 2016; Mallya & Fiocco, 2018). Moreover, caregivers exhibited cognitive impairment linked to stress (Vitaliano, 2011).

The regression estimate of 2.276 (p-value < .000) indicated a link between stress and the psychological adjustment of caregivers of children with thalassemia, as previously noted. The concept of adjustment can be elucidated through the lens of sadness, anxiety, and behavior, as noted in the introduction. Dirikkan et al. (2018) observed that stress resulted in the emergence of adjustment problems linked to depressive and anxious moods in caregivers. The caregivers may exhibit behavioral issues linked to substance abuse due to their work with a challenging clientele. Research conducted by The Recovery Village in 2020 indicates that caretakers occasionally misuse substances such as alcohol, stimulant pills, or illicit narcotics. An additional experimental study revealed that caregivers displayed signs of stress, despair, and anxiety. This indicated that caregivers were encountering these situations (Boots et al., 2018).

Due to the challenges encountered by caregivers of children with thalassemia, it is imperative for all impacted stakeholders to assist and support the caregivers by ensuring that issues are accurately detected and that they receive timely mental therapy. The issue of thalassemia requires the implementation of suitable strategies or preventive measures to mitigate the burden on caregivers of affected individuals. The study can be replicated on caregivers of diverse issues to facilitate future recommendations. A study has substantiated three adaptation strategies: hope, awareness, and therapy. These strategies are intended for caretakers of individuals with thalassemia. A qualitative study may be advantageous for exploring the comprehensive experiences of caregivers of children with thalassemia (Heidari, 2018).

Conclusion

There was a role of stress in affecting the cognitive functioning and psychological adjustment of caregivers of the children with thalassemia.

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