# Psycho-Social Challenges and Coping Strategies of Caregivers of Thalassemia Patients in District Gujrat

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## Abstract

Thalassemia is a chronic, life-threatening genetic blood disorder that has numerous socio-economic and health impacts on patients, caregivers and families globally. The issue of thalassemia is rapidly increasing among infants and children, and a large proportion of the affected population is living in developing countries like Pakistan. The patients suffering from the chronic issue bear symptoms such as pale skin, weakness, shortness of breath and jaundice. Thalassemia has severe complications with long-lasting consequences on the patients as well as their caregivers. Limited health care services, lack of social support, misconceptions about the condition, the stigma and discrimination within their families and communities can lead to disruption of their physical, cognitive, social and economic conditions. Several coping mechanisms are applied to deal with discomfort that could manage stressrelated demands that arise due to environmental transactions that eventually exceed personal resources. The present study examined the psycho-social challenges faced by caregivers of thalassemia patients and identified the coping strategies employed by these caregivers in Gujrat city. Researchers used the purposive sampling technique for this quantitative study to collect primary data through a structured questionnaire. The findings highlighted that the caregivers of thalassemia patients face various psychological challenges such as depression, fear of losing a loved one life, and feelings of isolation. This can negatively impact the overall well-being of the caregiver. Additionally, they face social challenges, including social stigma and limitations in maintaining social connections.

**Keywords:** Thalassemia, Genetic Blood Disorder, Caregivers, Psycho-social Challenges.

#### Introduction

Thalassemia is a chronic, life-threatening disorder that has numerous socio-economic and health impacts on patients, caregivers and families globally (Ahmadian, 2022). Thalassemia is a genetic blood disorder that involves the gathering of acquired blood problems, as described by the unusual creation of hemoglobin. The issue of Thalassemia is rapidly increasing among infants/children, and a large proportion of the population has to face morbidity and mortality worldwide widely, especially among developing countries like Pakistan (Nargis et al., 2023). The patients suffering from this chronic issue bear symptoms such as pale skin, weakness, shortness of breath and jaundice. According to the World Health Organization, out of total child births every year, 4.4% of children

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are affected by this genetic disease, which is increasing day by day due to the absence of essential nutritional and health awareness among families. The issue of thalassemia has severe complications with long-lasting consequences on the patients as well as their caregivers (Yousuf et al., 2022).

Multidimensional psycho-social challenges, including emotional distress, hopelessness, feelings of uncertainty regarding the future, social problems, financial strain, and lack of information about the issues continually faced by the patients as well as their caregivers (Askaryzadeh et al., 2023). Understanding these challenges and identifying effective coping strategies is crucial to support the well-being of both caregivers and patients. Usually, the parents are the prime caregivers to their affected children and play a critical role in helping affected children throughout their life journey (Aziz et al., 2022). The constant worry about the child's health and the uncertainty about the future cause emotional strain, and caregivers go through extreme psychological problems such as anxiety, depression, guilt, fear of losing a loved one life and feelings of helplessness because thalassemia requires consistent medical care, regular blood transfusions, medications, and specialized treatments. These expenses can impose a significant financial burden on caregivers (Tarım et al., 2022).

Caregivers often experience high emotional stress due to witnessing the physical and emotional pain endured by the child (Angane et al., 2022). They may struggle with managing their emotions and have difficulty finding joy or pleasure in activities they used to enjoy. Everyone has different situations and faces different problems, and their experiences with disease also vary from others. These psychological issues can also affect their ability to think clearly and process information effectively (Saqlain et al., 2022). The result of their condition might also lead to social withdrawal and isolation from supportive relationships. Continuous worry about their child's health can disrupt their daily routines and activities. Simple tasks such as household chores, work, sleeping schedule, or regular eating schedule may become challenging. Caregivers may experience a loss of interest, motivation, and satisfaction, leading to neglect of their well-being and responsibilities (Anwar et al., 2022).

In most developing countries like Pakistan, due to limited healthcare services, lack of social support and misconceptions about the condition, caregivers face stigma and discrimination within their families and communities (Ibrahim, 2021). This can lead to disruption of not only their physical and mental health but also create negative societal attitudes towards both caregivers and patients. All these challenges affect the caregivers mentally and physically because caring for a loved one requires immense dedication and strength. Still, caregivers need to remember to take care of themselves as well. For reducing and minimizing the effect of stress, they use different coping strategies for help (Cheraghi et al., 2022). Most guardians can effectively adapt to persistent sicknesses. Then again, a few guardians don't prevail with regards to adapting, the reasons of which incorporate the absence of admittance to substantial data about the illness, lack of legitimate strong sources, high treatment costs, state of mind, and social issues (Biswas et al., 2022).

Several coping mechanisms are used to deal with discomfort, such as negative or positive coping strategies, using religious beliefs and cultural rituals that inculcate the cognitive and behavioral efforts of an individual that could manage stress-related demands that arise as a result of the environmental transactions that eventually exceed the personal resources (Atiye et al., 2022). Coping strategies can vary greatly depending on the individual and their situation. Caregivers use coping strategies to deal with challenges, stressors, or difficult emotions. Coping strategies are a dynamic interchange between a person and the environment as the individual manages a complex problem or situation (Ahmadian et al., 2022). These strategies can include seeking social support, engaging in physical exercise, practicing mindfulness or meditation, doing religious activities for peace, seeking professional help,

and many others. Everyone chooses the different and most reliable method for resolving the problem. These strategies promote psychological well-being, resilience, and adaptation (Ahmadi et al., 2020). Caregivers who utilize coping strategies often experience reduced stress levels, increased resilience, and enhanced psychological well-being (Andriyani et al., 2022). Adopting a coping strategy can be influenced by various factors, including cultural and personal beliefs, access to resources, individual resilience, and the nature of the stressor or challenge. Personal characteristics of the caregivers, such as personality traits, self-esteem, and prior coping experiences, can shape coping strategies. Quality social support networks significantly influence coping behaviors (Anwar et al., 2022). Robust support systems provide emotional guidance, practical assistance, and validation, promoting adaptive coping. Cultural norms, beliefs, and values also influence the selection and acceptability of coping strategies. Effective coping strategies are associated with better mental health outcomes and improved overall functioning.

Thalassemia is a chronic and hereditary blood disorder that requires lifelong medical management and care. The present study examined the psycho-social challenges faced by caregivers of thalassemia patients and identified the coping strategies employed by these caregivers in Gujrat City. The study focused on exploring the role of caregivers in thalassemia care, which is associated with various psycho-social challenges that can impact their well-being and ability to cope effectively. By examining these challenges and coping strategies, the study aims to shed light on caregivers' unique experiences and needs in the context of thalassemia care.

## **Study Objectives**

- To examine the psycho-social challenges faced by caregivers of thalassemia patients in Pakistan
- To understand the association among psycho-social challenges and coping strategies adopted by the caregivers.

## **Materials and Methods**

This explanatory research was conducted in the Gujrat district of Pakistan to examine the psychosocial challenges and coping strategies of caregivers of thalassemia patients. Quantitative methods and techniques were applied, and the purposive sampling technique was adopted to collect primary data through a structured questionnaire. The participants of this study were the caregivers of thalassemia patients. Researchers visited thalassemia care centers of Gujrat city and personally met with the receptionist for patients and caregivers who visited the thalassemia care centers with their patients for fifteen days.

The researcher visited the thalassemia organization and interacted with their receptionist to discuss conducting the research study. The receptionist showed excellent behavior and very carefully listened to the researcher. Then, she guided the researcher through the roles and terms of the organization while touring the organization and interacting with the caregivers. The researcher met with caregivers and made them comfortable by getting friendly with them. Then, the researcher asked them about their experiences and guided them through the questionnaire; the researcher also gave information about how to respond to each item. 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. The respondents filled out a total of 260 questionnaires.

After the data was collected, it was edited and entered into SPSS. When the data was entered, tables for 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 designed to check the relationship between independent and dependent variables and to carry out further statistical analysis.

## **Theoretical Framework**

Coping theories have been divided into two parameters: Trait-oriented theories versus state-oriented theories and micro-analytic approaches versus macro-analytic approaches. The trait-oriented theories focus on the early recognition of a person's resources and tendencies related to coping. In contrast, the state-oriented theories focus on the actual coping of an individual and the outcome of his application of coping methods or strategies. On the other hand, the micro-analytic approach studies a wide variety of specific and concrete coping strategies, while the macro-analytic approach concentrates on fundamental and abstract coping methodologies. These approaches are interconnected with each other. The present study aims to compare these theories and their perspective one by one and give the details of the most relevant theoretical perspective with the study.

## **Macro-analytic Trait Oriented Theories**

Macro analytic, trait-oriented coping theories focus on understanding how individuals employ specific coping strategies and mechanisms to deal with stress, adversity, and challenging situations. These theories emphasize the role of personality traits in shaping an individual's coping responses and their effectiveness in managing stressors.

## **Monitoring and Blunting Theory**

The monitoring and blunting theory is a psychological theory that focuses on individual differences in coping strategies and information processing in response to stressful or threatening situations. This theory explains that one can reduce the impact of a stressful stimulus by using cognitive processes (e.g. denial distraction). In contrast, individuals with a blunting coping style tend to adopt a more avoidant and selective information-processing strategy when faced with stress.

#### **Model of Coping Modes (MCM)**

This theory is an extension of the monitoring-blunting model and has some connections to the repression-sensitization theory. Coping modes refer to individuals' different strategies or approaches to deal with stress, adversity, or challenging situations. Various models have been proposed to describe coping modes based on theories and perspectives. These theoretical assumptions advocate that every individual choose the coping method according to his psychological understanding and tendency to cope with the situation and select the best strategies according to his perspectives.

#### **Macro-analytic State-oriented Theories**

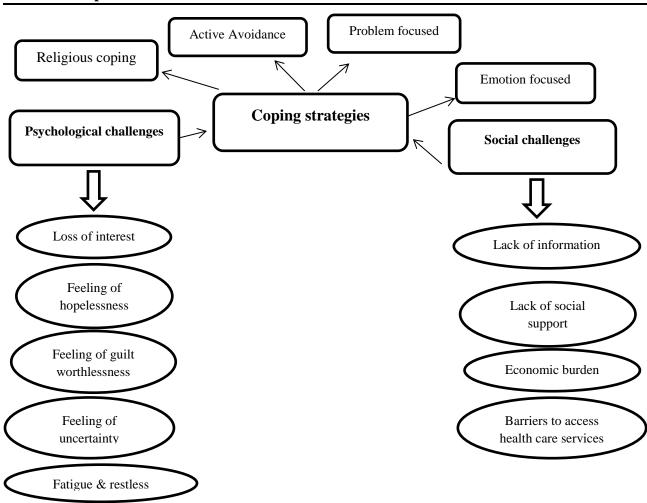
The theory mentioned by Freud (1926) is one of the earliest macro-analytic state-oriented coping methods. Another approach that gained popularity in this area is the theory of Richard Lazarus and Susan Folkman (Folkman, 1997; Lazarus & Folkman, 1984). It is also known as the transactional model of stress and coping. This model emphasizes the dynamic interaction between an individual and their environment regarding stress. According to this model, stress is not solely determined by external events but depends on the individual's appraisal and interpretation of those events. It proposes that individuals engage in two primary cognitive processes when faced with a potential stressor: primary appraisal and secondary appraisal. Lazarus and Folkman identified two general types of coping strategies. For example, someone facing a health problem might confide in a friend

or engage in relaxation techniques to reduce anxiety. Lazarus also classified eight functions that most of us use for active coping such as:

- Self-control: when a person tries to control his emotions in response to stress.
- Confrontation: when a person faces pressure and retaliates to change the situation and bring it back in his favor.
- Emotional distancing: when we stay indifferent to what is happening around us and prevent the distress from controlling our actions.
- Strategic problem-solving: where we implement specific solution-focused strategies to get through the tough time and redirect our actions accordingly.
- Social support is when someone talks to others, like family or friends, to seek social support.

According to the Lazarus framework, coping strategies vary from person to person and from time to time. A host of experiments and literary reviews have proven that the stress management techniques we use help restore functions at the molecular levels of the body (Scheier & Carver, 1985). After that, caregivers may utilize various coping strategies to manage the stress. Lazarus and Folkman's model distinguishes between problem-focused coping and emotion-focused coping.

Figure 1: Schematic representation of factors affecting coping strategies among caregivers Of Thalassemia patients



# **Study Hypothesis**

- H1: Higher the level of psychological challenges, higher the level of adoption of coping strategies by caregivers.
- *H2:* Higher the level of social challenges, higher the level of adoption of coping strategies by caregivers.

# **Results and Discussions**

# **Descriptive Analysis**

The study was aimed at investigating the psychological and social challenges faced by caregivers of thalassemia patients and to identify the coping strategies adopted by them to reduce the mental stress. This study examined the relationship of independent factors with the dependent variable. This section has been further divided into three sections, the socio-demographic information about the respondents, description on independent variables and description of dependent variable.

<b>Demographic Characteristics</b>	Description of characteristics	%	N
Residential Areas	Urban	39.1	102
	Rural	60.5	158
Gender	Male	36.8	96
	Female	62.8	164
Participant's Age	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
Education Level	0-5	53.3	139
	6-10	23.4	61
	11-16	23	60
Family System	Nuclear	74.7	195
	Joint	24.9	65
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
<b>Monthly Family Income (PKR)</b>	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

The table 1 provides information regarding the demographic characteristics of the study participants. A large proportion 60.5% of participants is living in rural areas of district Gujrat. The table also indicated that most of the caregivers 62.8% were females with different age groups. Only a few number 23% of participants have their education level higher than matriculations. Maximum participants 74.7% are living in nuclear family system and out of total most of the participants are related with agriculture 28.7%. The findings intimated that a huge proportion of population 44.4% have 50001-60000 rupees monthly income.

Tabl	e 2: Description of psycho-social challenges	(independen	t variables)		
<b>B</b> 1	Psychological Challenges	SA %(f)	A %(f)	SDA %(f)	DA %(f)
1	You do not feel pleasure in your daily	81.6 (213)	18.0 (47)	0	0
	activities.				
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)
<b>B2</b>	Social Challenges	SA %(f)	A %(f)	SDA %(f)	DA %(f)
1	Adequate awareness about disease.	57.5 (150)	34.5 (90)	1.9 (5)	5.7 (15)
2	Information about the disease from media.	8.4 (22)	10.0 (26)	19.5(51)	61.7(161)
3	You are not aware of the nature of the	55.2 (144)	39.8	1.1 (3)	3.4 (9)
	disease.		(104)		
4	Awareness regarding treatment of this	53.6 (140)	30.3 (79)	2.3 (6)	13.4 (35)
	disease.				
5	Where to seek information about the	50.6 (132)	31.0 (81)	4.2 (11)	13.8 (36)
	disease.				
6	Where to seek professional help.	53.3 (139)	31.8 (83)	43 (11)	10.3 (27)
7	You know this is a genetic disease.	6.9 (18)	5.7 (15)	13.8(36)	73.2(191)
<b>B3</b>	<b>Economic Challenges</b>	SA %(f)	A %(f)	SDA %(f)	<b>DA</b> %(f)
_1	The expenses of treatment are very high.	78.9 (206)	19.9 (52)	.4 (1)	.4 (1)
3	Arranging blood donors proves very costly.	65.9 (172)	32.2 (84)	.4 (1)	1.1 (3)
3	There is no support to bear financial	60.9 (159)	33.3 (87)	1.5 (4)	3.8 10
	burden.				
4	No financial support from government	70.1 (183)	28.7 (75)	.8 (2)	0
5	Financial help in treatment of this disease.	19.2(50)	13.4 (35)	21.1(55)	46.0(120)
6	Family expenditure is spent on treatment	69.3 (181)	29.5 (77)	0	.8 (2)
7	Visiting health care facility is an extra	69.7 (182)	29.5 (77)	.4 (1)	0
	burden.				
				<u>-</u>	

Table 2 shows the description of participants' psycho social challenges (independent variables), different challenges such as psychological challenges, social challenges and economic challenges were measured through different indicators. The findings highlighted that people lose their interest because of their child health as we can see in various considered items; most of the patient's parent

do not feel pleasure in their daily life activities. In item results shows that parents gradually lost interest in everything and were unable to perform their task properly. All the data shows that majority of parents do not feel pleasure and satisfaction during performing their daily life task.

Table 2 represents the social challenges such as lack of information and knowledge about the disease and majority of the participants 90% parents agree with it. A large portion 19% parent got information about the disease from social media and majority of the parent have no any awareness regarding disease. Huge proportion 96% parents are not aware about the nature and treatment of disease. All the data indicate that majority of the parents do not have knowledge and information about the disease and they did not know about the nature, treatment and from where to they seek professional help for treatment.

Similarly the results from table 2 indicated the economic challenges and results highlighted the expenses of treatment of disease are very high and 98% parents are agreeing with it. Arrangement of blood donor on constant basis sometime proves very costly and majority of parents 97.5% parent are agree. The families did not have any financial support from relatives, government and 32% families agree that they have some non-governmental agencies which provide financial help to them. All the results prove that majority of parents face economic burden and they have not any financial support by government.

Table	Table 3: Description of coping strategies (dependent variables)							
<b>D</b> 1	Active avoidance coping	SA %(f)	A %(f)	SDA %(f)	DA %(f)			
1	You avoid thinking about it.	81.6 (213)	18.0 (47)	0	0			
2	You try to stay busy to cope with the	68.6 (179)	31.0 (81)	0	0			
	situation.							
3	You try to think positive.	65.5 (171)	34.1(65.5)	0	0			
4	You prefer to stay alone for a while.	52.9 (138)	38.7 (101)	2.3 (6)	5.7 (15)			
5	You do household chores to keep yourself	56.7 (148)	42.5 (111)	0	.4(1)			
	busy.							
6	You try to divert your attention during	60.9 (159)	38.7 (101)	0	.4(1)			
	activities.							
<b>D2</b>	Problem focused coping	<b>SA</b> %( <b>f</b> )	A %(f)	SDA %(f)	<b>DA</b> %(f)			
_1	You prefer to use self-medication at home.	22.2 (58)	28.4 (74)	16.5 (43)	32.6 (85)			
2	Professional medical doctors for	78.9 (206)	19.2 (50)	.8 (2)	.8 (2)			
	treatment.							
3	You use herbal medicine to cure the	22.2 (58)	28.4 (74)	16.5 (43)	32.6 (85)			
	disease.							
4	Different sources /for recovery.	57.9 (151)	35.2 (92)	3.4 (9)	3.1 (8)			
5	Allopathic medicine for treatment.	74.7 (195)	24.9 (65)	0	0			
6	You ask other people about their	76.6 (200)	22.2 (58)	.4 (1)	.4 (1)			
	experience.							
<b>D3</b>	Religious coping	<b>SA</b> %( <b>f</b> )	A %(f)	SDA %(f)	DA %(f)			
1	You frequently pray for healing of your	82.0 (214)	17.2 (45)	0	.4 (1)			
	child.							
$\frac{2}{3}$	You occasionally visit shrine for praying	62.5 (163)	30.7 (80)	2.7 (7)	3.8 (10)			
3	You engage in performing religious	65.1 (170)	34.1 (89)	0	.4 (1)			
	practices.							

4	You prefer to visit spiritual healer	42.5 (111)	36.4 (95)	8.0 (21)	12.6 (33)
5	You engage yourself in pray more than	66.7 (174)	32.6 (85)	.4(1)	0
	usual.				
<b>D4</b>	Emotion focused coping	<b>SA</b> %( <b>f</b> )	A %(f)	SDA %(f)	DA %(f)
1	Discuss feelings with friends for mental	63.2 (165)	32.6 (85)	.8 (2)	3.1(8)
	peace.				
2	You seek emotional strength from other.	45.2 (118)	42.1 (110)	4.2 (11)	9.0 (21)
3	You keep crying for hours in loneliness.	14.2 (37)	21.1 (55)	18.8 (49)	45.6 (119)
4	You try to get sympathy from others.	36.0 (94)	44.4 (116)	4.2 (11)	14.9 (39)
5	Try to avoid talking and interacting with	32.2 (84)	26.1 (68)	9.6 (25)	31.8 (83)
	people.				
6	Try to relate with people of similar	71.3 (186)	25.7 (67)	.8 (2)	1.9 (5)
	experience.				

According to findings presented in table 3 of the description of coping strategies (dependent variables), the caregivers avoid thinking about the situation. They try to stay busy to cope with the problem and think positively to cope with the situation. The parents prefer to stay alone and do household chores to keep themselves busy. Findings show that parents try to divert their attention by doing various activities and interacting with people so that they can shift their focus. The results indicate that most parents try to think positively, engage in negative thinking, and do various household activities to cope with situations.

Table 3 also highlights the findings regarding problem-focused coping adopted by caregivers, and results indicated that people prefer to use self-medication at home and do not prefer to consult a professional doctor for treatment. 52% of parents use herbal medicine to cure the disease, and 93% of parents use different sources to search for recovery methods. Parents also prefer to use allopathic medicine for treatment and ask other people about their experience with the disease. 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 treatment method.

Results concerning religious coping strategies are also presented in table 3, and findings demonstrated that parents frequently pray for their children, and 100% of parents give strongly positive responses. People prefer to visit the shrines to pray for their children's health, and 93% are given positive responses and engage themselves in performing religious practices. Out of a total, 80% of parents prefer to visit spiritual healers to seek advice for a cure and engage themselves in prayer more than usual, and 99% of parents responded positively. Parents leave their affairs to Allah and have hope for some miracle which can cause their child's recovery. All the results indicate that most parents practice religiously to cope with the situation.

Similarly, table 3 discusses emotional coping strategies. The results show that parent discusses their feeling with friends for mental peace, and most parents share their feelings with friends to cope with the situation. 87.3% of parents seek emotional strength from others, and parents cry for hours in loneliness. Most of the time, parents try to avoid talking and interacting with people and relate themselves to people who have similar experiences. They also keep sitting in the corner for extended periods, thinking about the stressful situation. All the results indicate that the majority of the parents try to share their feelings with friends for mental peace and seek emotional strength and sympathy from others to cope with the situation.

## **Test of Normality**

A normality test determines whether sample data has been drawn from a normally distributed population. The two fundamental normality tests, the Kolmogorov-Smirnov test and the Shapiro-Wilk test are the most broadly utilized strategies to test the normality of the information.

Table 4: Distributed characteristics of study population								
	Kolmogorov-Smirnova			Shapiro-				
	Statistic	df	Sig.	Statistic	df	Sig.		
Social Challenges	.078	260	.001	.985	260	.009		
<b>Psychological Challenges</b>	.051	260	.200*	.993	260	.218		
Coping strategies	.067	260	.006	.987	260	.018		

In table 4, the Kolmogorov-Smirnova and Shapiro-Wilk test was applied to check the assumptions of normality. The P value of the test for social challenges is .009, more significant than the significance level (0.05). Conversely, the P value for psychological challenges is .218, which is also more significant than the significance level. The null hypothesis was accepted in this case, stating that the data is usually distributed. Similarly, table 4 also shows the normality of coping strategies. The P value of the coping strategies, i.e. (.018), is g, more significant than the significance level. That indicates the null hypothesis was accepted, stating that the data is usually distributed.

# **Regression Analysis**

There were two independent variables in the study. These are psychological challenges and social challenges. The dependent variable was coping strategies. Multiple regression analysis was performed to determine the best possible model for predicting the dependent variable by using independent variables. Multiple regression analysis was performed using the enter method, also known as the forced entry method. In this method, all independent variables (predictors) are simultaneously entered into the regression equation. This method is used to address two questions. Firstly, this method estimates the size of the overall relationship between the predictor variables and the predicted variable. Secondly, it assesses how much each variable contributes to that relationship. Before the multiple regression analysis was employed, the assumptions of using this method were checked. Diagnostic tests and graphs were used to check these assumptions. The Kolmogorov - Simonov test was applied to check the assumption of normality. The p-value of this test was more significant than the significance level (0.05). In this case, the null hypothesis was accepted, which stated that data is usually distributed. Further, a P-P plot and histogram with a normal curve were also generated to indicate the normality of the data. The results of regression analysis as shown

<b>Table 5:</b> 1	Model summ	ary		
Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.492 <sup>a</sup>	.242	.236	5.65513

Table 5 shoes the value of R-square that indicates the strength of linear relationship explained in the dependent variable, coping strategies by both independent variables. The value of R-square in this case is 0.242 which means that only 24.2 % of the variation in coping strategies is explained by the considered independent variables.

Table 6: Analyses of Variance (ANOVA)							
Mod	lel	Sum of Squar	res Df	Mean Square	F	Sig.	
1	Regression	2629.609	2	1314.804	41.113	.000 <sup>b</sup>	
	Residual	8218.987	257	31.980			
	Total	10848.596	259				

From table 6 regression sum of squares is less than residual sum of squares; it means that less variation is explained in dependent variable due to all independent variables. The same was the situation in the case of R-square. The significant result of the F-test and P value leads to the rejection of hypothesis that together all the independent variables do not affect the dependent variable, coping strategies.

Model		Un-standardized Coefficients		Standardized Coefficients	t	Sig.
		В	Std. Error	Beta	<u> </u>	
1	(Constant)	61.016	5.700		10.704	.000
	Psychological Challenges	.281	.052	.317	5.420	.000
	social Challenges	.253	.053	.277	4.731	.000

Table 7 represents the values of coefficients that predict the strength of the relationship between the independent and dependent variables. Regression coefficients have shown the importance of independent variables in making regression models. It is explained as regression coefficients. Psychological and social challenges influence coping strategies. This influence is significant because the p-value of the predictor is less than 0.05. The regression coefficient of psychological and social difficulties has depicted that changing one unit score in the psycho-social challenges causes .317 for the psychological challenge and 0.277 score change for the social challenge in the dependent variable. Independent variables have a significant influence on the dependent variable.

#### **Discussions**

The present study investigated the psychological and social challenges and coping strategies adopted by the caregivers of thalassemia patients in Gujrat city. The Pearson correlation test results suggested that the psychological and social difficulties taken as independent variables have positive associations with the dependent variable, coping strategies. The regression model also significantly predicted the relationship between independent and dependent variables. The study's findings revealed that effective coping strategies are necessary for the well-being of caregivers because effective coping styles can lead toward positive outcomes such as reducing stress levels, mental peace, and improving the quality of life of caregivers.

Firstly, the psychological challenges and their relation with coping strategies were examined. The significant psychological challenges experienced by caregivers are the loss of interest and pleasure in daily activities, social withdrawal, hopelessness and uncertainty. Similar findings have also been reported by many other researchers, such as in a study conducted by Simons et al. (2015) it was found that the parents often experience emotional distress resulting from the pain and suffering of their child (Simons et al., 2015). Work supports the loss of interest in everything due to worries about their

child's health (Aziz, 2022). The feeling of hopelessness regarding the healthy life of their child is linked with the work of (Atiye et al., 2022) and also in line with the findings of (Anwar, 2022). Moreover, the researcher examines the relationship between social challenges and coping mechanisms in the present study. Researchers analyzed that one of the main reasons for this disease is a lack of awareness and knowledge; this finding is also supported by (Askaryzadeh et al., 2023) families who don't have adequate information about thalassemia. They did not know it was a genetic disease, and from there, they sought professional help, so that's why it is increasing day by day in Pakistan. Another study (Biswas & Lo, 2022) supported the findings that lack of knowledge, ignorance of the disease, and lack of premarital screening practices play a significant role in the propagation of this disease. Furthermore, it has also been found that there is a substantial economic

burden on the caregivers of Thalassemia patients regarding treatment and seeking support services for this disease. The present study revealed that thalassemia children must regularly attend the hospital for blood, which creates emotional or financial strain on caregivers. Ahmadian (2003) also argues in his study that thalassemia children have to regularly attend blood centers for blood transfusions to survive, which creates a lot of burdens on families.

The study also identified various coping strategies the caregivers utilized to cope with stressful situations and improve their overall well-being. The caregivers adopt active avoidance coping, problem-focused, religious coping and emotional coping strategies. Other researchers have also supported these findings. According to Andriyani (2022) coping strategies were identified as efforts to reduce the adverse events in life where there was physical and psychological pain. According to Tsiantis et al., 1996), coping is a dynamic interchange between a person and the environment as the individual manages a difficult problem or situation. The study (Cheraghi, 2022) suggested that faith and religious practices were the major adaption coping strategies used by the participants. Overall, the coping mechanism may differ in nature. Still, they provide relief from stressful situations either by avoiding or adopting ways to deal with stress that may help improve the well-being of caregivers.

## Conclusion

The study concluded that caregivers of thalassemia patients face various psychological challenges such as depression, fear of losing a loved one life, and feelings of isolation. This can have a negative impact on the overall well-being of the caregiver. Additionally, they face social challenges, including social stigma and limitations in maintaining social connections. However, the findings of this present study also revealed several coping strategies employed by caregivers to reduce the impact of these challenges. It was observed that support from family and friends plays a vital role in helping caregivers cope with the psychological and social pressure they face. Seeking professional help, engaging in relaxation activities, and adopting positive thinking were effective coping strategies. Further, the present study concluded that it is evident that providing adequate support and resources for caregivers is essential in reducing the negative impact of psychological and social challenges. Healthcare services and support organizations should work to enhance the availability of support, counselling services, and educational programs to help caregivers develop better coping strategies.

#### Recommendations

- The present study was helpful for healthcare professionals to develop interventions to address caregiver-specific concerns, enhance their overall quality of life, and establish support groups for caregivers to provide a space for sharing experiences and emotional support.
- The present study also recommended raising awareness about thalassemia and its impact on family members.

- Further, studies can be conducted on the importance of caregiver self-care, which encourages caregivers to engage in activities that give them relaxation and promote adaptive coping strategies that educate and make 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 significant patients.

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