

## THE MEDIATING ROLE OF RESILIENCE IN THE RELATIONSHIP OF COPING STRATEGIES AND PSYCHOLOGICAL WELL-BEING OF THALASSEMIC ADOLESCENT PATIENTS IN KARACHI, PAKISTAN

Muhammad Akram<sup>\*1</sup>, Dr. Khalida Tanweer<sup>2</sup>

<sup>\*1</sup>PhD Social Sciences -Psychology Major, Faculty of Social Sciences SZABIST University, Karachi Campus;

<sup>2</sup>Professor, Department of Social Sciences, SZABIST University, Karachi Campus

Received: 05 May, 2024

Revised: 05 June, 2024

Accepted: 17 June, 2024

Published: 30 June, 2024

### ABSTRACT

**Background:** Thalassemia is one of the main chronic hereditary diseases characterized by severe symptoms of anemia. Also, it has negative effects on patients' mental health. However, few researches have studied the different psychiatric aspects of this disease and the psychological and social needs of thalassemic patients.

**Objectives:** The aim of the present study was to investigate the mediating role of Resilience in the relationship of Coping Strategies and Psychological well-being of Thalassemic Adolescent Patients in Karachi, Pakistan.

**Methods:** The statistical population of this study included adolescent patients age ranging from 13 to 18 years with thalassemia major. According to the method of sample size determination in behavioral studies, a minimum sample size of 134 patients is determined for this research through G\* power, with effect size 4, probability of error .05 and power .95 (Faul et al, 2007). This is a cross-sectional study that was conducted on thalassemia centers for collection of data. This study is quantitative and correlational approach to examine the relationship between three variables. The data for this study will be collected by using Demographic Sheet, Jalowiec Coping Scale (JCS), Connor-Davidson Resilience Scale (CD-RISC) and Reef Psychological Well-Being Scale (RSPWB). Demographic information sheet comprises of information on gender, age, level of education, blood transfusion frequency on monthly basis, family income and any psychological disease history.

**Results:** The results indicated that resilience and coping strategies have positive effects on psychological well-being and its subscales including self-acceptance, positive relationship with others, autonomy, personal development and purposeful life of thalassemia major patients (p <0.05).

**Conclusion:** According to the results, regarding the effectiveness of resilience and coping strategies on the psychological well-being of thalassemic patients, the present study could introduce effective solution for development of psychological well-being and improvement of overall mental health of patients with thalassemia major.

**Keywords:** resilience, stress management, psychological well-being, thalassemia major

### INTRODUCTION

A genetic condition known as -thalassemia is brought on by abnormalities in the -globin genes, which completely prevent or drastically reduce the manufacture of normal -globin chains. In Egypt, where the carrier incidence was 9%–10%, -thalassemia is a serious public health issue. The clinical manifestations of the genetic condition are quite diverse and range in severity from clinically silent heterozygous -thalassemia to severe

transfusion-dependent -thalassemia major (-TM). In addition to endothelial and vascular dysfunctions, elevated oxidative stress with consequent atherosclerotic development, and cardiovascular illnesses, patients with -TM present clinically with severe transfusion-dependent anaemia. Homocysteine (hcy) elevated plasma levels have been identified as a separate risk factor for the emergence of these problems (Elmawla et al., 2016).

Recently, better transfusion protocols and consistent chelation programmes have significantly increased the life expectancy of patients with  $\beta$ -thalassaemia major ( $\beta$ -TM). According to a recent study, 91% of women with thalassaemia who become pregnant naturally or as a result of gonadotropin-induced ovulation successfully gave birth to healthy infants. However, pregnancy in thalassaemic women is thought to have a considerable risk, necessitating expert supervision. The rise of new issues in thalassaemic individuals, such as autoimmune diseases, nephritis, diabetes, arthritis, fibromyalgia, and asthma, was influenced by increased survival. Women of reproductive age frequently have autoimmune illnesses, which either become fulminant or are extremely difficult to control during pregnancy. Numerous immunosuppressive medications have been discovered to be detrimental to fetus, making novel medications like cyclosporine A that could protect both the mother and the fetus crucial (Agapidou et al., 2013).

Thalassaemia major and thalassaemia intermedia cover a wide range of clinical and laboratory problems but lack a definite molecular connection. Thalassaemia major patients are often those who seek medical attention within the first year of life and go on to require routine transfusions in order to survive. Those with thalassaemia intermedia are those who present later or rarely require transfusions (Ghasemi et al., 2014).

### **Psychological Hazards of Thalassaemia**

The effect of stress on life differs at various periods, particularly throughout childhood and adolescence, which can be termed as a stage for development with numerous conflicts and difficulties. Some teenagers struggle to manage their disease when faced with such difficulties, but others are able to do so by employing various coping mechanisms (Yi-Frazier et al., 2015). As a result, their resilience, which is frequently brought up in discussions on the transition from infancy to adolescence (Tusaie et al., 2007) as a crucial trait that is required for teenagers' adaptation, might be credited with this effective performance (Ahern et al., 2008). Additionally, resilience is described as utilization of that person's capability for adjusting in challenging circumstances, which is influenced by a number of different factors. The ability to manage stress is one aspect of resilience (Parviniannasab et al., 2020).

Coping process was defined by Lazarus and Folkman (1984) as a process in which the patient attempts to manage the stress by using cognition and behavioral control. These attempts are both external (courageous or focused on problems) and internal as well (defensive or focused on emotions). Due to their short lifespan and potential for despondency, thalassaemia patients must learn how to live their lives while achieving the highest possible level of psychological well-being.

Patients with thalassaemia feel different from their peers and develop negative thoughts about their life, a sense of guilt, increased anxiety, and low self-esteem; their behavioral profile is similar to normal individuals, but many of them may develop severe psychosocial problems because of difficulties in complying with the painful chelation; male patients, in particular, show oppositional defiant disorder. Within the family, concerns for the future of a thalassaemic child may contribute to worsening of relationships among members, and to increase marginalization and isolation. (Saini et al., 2007).

In addition, Psychological wellbeing which is defined as an individual's perception of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, and expectations, is often limited by the chronic illness. Many neurotic symptomatology have been found in children with thalassaemia major in different surveys. Depressive moods and anxiety were diagnosed in children with thalassaemia major. Screening for anxiety and depression in patients with thalassaemia is essential. (Telfer et al., 2005).

The effect of stress on life differs at various periods, particularly throughout childhood and adolescence, which can be termed as a stage for development with numerous conflicts and difficulties. Some teenagers struggle to manage their disease when faced with such difficulties, but others are able to do so by employing various coping mechanisms (Yi-Frazier et al., 2015). As a result, their resilience, which is frequently brought up in discussions on the transition from infancy to adolescence (Tusaie et al., 2007) as a crucial trait that is required for teenagers' adaptation, might be credited with this effective performance (Ahern et al., 2008).

Thus, appropriate treatment of these conditions may improve patients' health-related psychological wellbeing. The impact of thalassaemia major and their associated complications of psychological wellbeing are largely known. Psychological support therefore

seems to help reduce the emotional burden of children with  $\beta$ -thalassemia major and their families (Aydinok et al., 2005). Psychosocial support aimed at reducing emotional distress, improving compliance to chelation therapy, and strengthening the coping strategies for better integration into daily life is therefore necessary. Aydinok et al., (2005) found that the frequency of psychopathology is higher in patients with thalassemia compared with the normal population; this supports the need for lifelong psychological support to prevent mental health issues among patients with thalassemia and their parents.

Some teenagers struggle to manage their disease when faced with such difficulties, but others are able to do so by employing various coping mechanisms (Yi-Frazier et al., 2015). As a result, their resilience, which is frequently brought up in discussions on the transition from infancy to adolescence as a crucial trait that is required for teenagers' adaptation, might be credited with these effective coping skills and resilience training (Ahern et al., 2008).

Therefore, there is a need to implement such type of coping strategies in order to enhance the resilience that will eventually boost the psychological well-being of adolescents (Tusaie et al., 2007). Thalassemia is included in one of the main chronic disorders transmitted through genes and resulting in hemoglobin shortage in patient's blood. The recognition and management of the psychological problems that accompany chronic physical illnesses including thalassemia would optimize treatment outcomes and psychological wellbeing of such patients.

### **Prevalence of $\beta$ -thalassemia in Pakistan**

In Pakistan, the carrier rate fluctuates between 5-8%, resulting in around 9.8 million carriers of the entire population, and approximately 5000 children are diagnosed with beta thalassemia each year. The main cause of high frequency in Pakistan is consanguinity. Pakistan is a South Asian country which is located almost on the thalassemia belt, with roughly 26,000 thalassemia patients (Rezaei et al., 2015) and prevalence of which ranges from 2.5% to 15% in diverse locations of the country.

Lamki et al., (2006) investigated the impact of psychosocial factors on thalassemia effected patients and families, as well as the psychological aspects that may influence patients' and families' adherence to therapy. The findings revealed that families faced a

number of challenges, including financial crisis, work issues and a reduction in the quality of life.

Pakistan has one of the highest thalassemia burdens in the world. The country's generally stated figure is 100,000 transfusion-dependent thalassemia patients. (Mirza et al., 2013). The number of thalassemics in the country is thought to be increasing in the absence of a unified national policy and strategic plan, but the exact burden of the disease is unknown. As a result, despite being a preventable blood illness, thalassemia continues to rise in Pakistan, causing suffering for the affected patients and eventually their families. Furthermore, it places a significance of demand on the already overburdened national health-care system, particularly the blood transfusion system.

As there is a 25% chance that the baby will be born with thalassemia major, a 50% chance that the baby will be born with thalassemia trait, and a 25% chance that the baby will be normal, if the couple is found to be thalassemia carriers, the female should undergo chronic villous sampling (and then PCR) at 10–12 weeks of gestation to determine the status of the fetus (Lamki et al., 2006). The couple should be provided pregnancy termination if the baby is discovered to have significant thalassemia, as this is now done with religious experts' approval. However, this problem still exists because many thalassemic families in our nation are unaware of it and choose not to have thalassemia prenatally detected (PND) in every pregnancy. PND was first made available in Pakistan in 1994, and major cities including Karachi, Lahore, Rawalpindi and Multan all have it. A total of 3000 PNDs have been conducted in these 16 years whereas between 5000 and 7000 babies are born annually. This shows that 80–90% of engaged couples are not using this service. The low use of services was attributed to a number of factors including low awareness, difficult access, and delays in seeking help. Religious convictions and high costs of detection are also included in these factors (Mirza et al., 2013).

Even though routine blood supplies and continuing medical care have lot of contribution in increasing survival rate for beta-thalassemia major patients, obtrusive approaches and consequences related to transfusion of blood have contributed in various physical problems like facial bones abnormalities, developmental delay and diabetes mellitus, along with these problems some splenomegaly and psychological problems as well. The psychological

problems included depression, anxiety and emotional & behavior disorders (Kosaryan et al., 2019).

### **1.1 Theoretical framework**

#### **Resilience in Illness Model (RIM)**

This model is used in this study as the benchmark for theoretical framework. Haase in 2014 developed and implemented the RIM model for diseases which are chronic, particularly in children and adolescents with cancer. This model emphasized on the risk factors as well as the protective factors for resilience. These factors which are included in this list are spirituality, hope, courage and social support. These factors have lot of impact on the patient and they might enhance resilience or they might hamper the coping skills, if they are not contributing for the betterment of the patient (Haase et al., 2014).

RIM employs an approach which is comprehensive and it is based on the progression and properties of resilience among the patients with diseases which are chronic in nature (Haase et al., 2014). They can be regarded as an essential step towards improvement of the quality of palliative care, health level and patients' ability to adapt to the chronic disease. A review of the chronic disease literature suggests a link between coping resilience and coping strategies (Messinger, 2017).

### **1.2 Purpose of the Study**

The main purpose of this study is to measure the correlation of coping strategies and psychological well-being and the mediating role of resilience in the relationship of coping strategies and psychological well-being of the adolescent thalassemia patients.

Even though the relationship between resilience and involvement of coping mechanisms in making predictions resilience has already been acknowledged in some previous studies but there has yet to be a study in Pakistan on the implementation of stress coping techniques, resilience and its influence on the psychological well-being of patients with thalassemia major. After taking into consideration, the chronic nature of thalassemia and the nature of resilience which is context based, sophistication, and multidimensionality, as well as the fact that various communities and cultures have different interpretations of resilience, conducting this research is appeared to be critical.

Furthermore, accepting the efficacy of coping strategies for stress management and resilience in

adolescents with beta-thalassemia major can help to facilitate the psychological well-being needed for an accurate conclusion and psychological well-being.

### **1.3 Significance of the Study**

Resilience is a critical human ability for successfully adapting to risk factors. Resilience is defined in medicine and psychology as effective health and unplanned recovery, as well as the ability to re-establish emotional stability in challenging situations; resilience describes traits that contribute to improving the frequency and rate of healing process after stress. Resilience can also refer to the continuous interaction of positively adapting to adversity and challenging conditions. Perfecting resilience and raising one's tolerance cutoff point for these interactions can change one's feeling of helplessness in difficult conditions and improve one's ambience, physical and psychological health. Resilience aids in the reduction of stress, the development of coping strategies, and the enhancement of appropriate defense mechanisms in people suffering from stressful illnesses.

Individuals who have high resilience have lower levels of avoidance, allowing them to survive with disruptions caused by chronic conditions, and they do not tend to magnify underlying condition. According to research, resilience is related to social interaction, hopefulness, strength, and functional mobility.

### **1.4 Research Questions**

This study answered the following question:

- Is there any relationship of emotional support in enhancing the coping ability of adolescent thalassemia patients?
- Is there any relationship of optimism in enhancing the psychological well-being?
- Is there any correlation between coping strategies and psychological well-being of the adolescent thalassemia patients?
- Is there any mediating role of resilience in the relationship of coping strategies and psychological well-being of the adolescent thalassemia patients?

### **1.5 Objectives**

The objectives of this study are as follows:

- To find out the relationship of emotional support in enhancing the coping ability of adolescent thalassemia patients.



- To find out the relationship of optimism in enhancing the psychological well-being of adolescent thalassemia patients.
- To find out the correlation (if any) between coping strategies and psychological well-being of the adolescent thalassemia patients.
- To find out the mediating role (if any) of resilience in the relationship of coping strategies and psychological well-being of the adolescent thalassemia patients.

### 1.6 Hypotheses

- There is a relationship of emotional support in enhancing the coping ability of adolescent patients.
- There is a relationship of optimism in enhancing the psychological well-being of adolescent patients.
- There is a correlation between coping strategies and psychological well-being of the adolescent thalassemia patients.
- There is a mediating role of resilience on the relationship of coping strategies and Psychological well-being of the adolescent thalassemia patients.

### LITERATURE REVIEW

In beta-thalassemia like other chronic disease, there is lot of burden in terms of clinical treatment as well as psychological and social burden on the family as well which eventually affects the mental health of the patient. So, it is very essential that should be a study on the factors that contribute towards the psychological burden on the patient and to investigate the distress level and a treatment plan for minimizing the impact of these factors in order to improve the quality of life and to improve their ability to be a productive part of the society. When we talk about the care givers and parents of the patient having any chronic disease, it is evident through many researches that there is a lot of pressure on them which eventually hamper the well-being of the patient. They are not only concern about the life expectancy of their child but they are also concerned about the child's life goal and achievements and quality of life. A patient having such chronic disease and his/her treatment eventually may impact the family stability and dynamics of the family (Parker et al., 2004).

Patients of  $\beta$ -thalassemic go through an intense psychological impact which caused hopelessness,

emotional burden; low-self-esteem and they have difficulty in social integration. There are lot of surveys which depicts that such patients have negative thoughts related to the activities which they can't do like other normal people may have, they have guilt, anxiety and low self-esteem. The main reason of these psychological issues is mainly due to their incapability for normal social interactions and adjustment in situations which are painful for them. This leads to further hampering and worsening the relationship of such patients with their families and eventually produce marginalization and isolation for such patients (Yi-Frazier et al., 2015).

As far as medical treatment is concerned, there is lot of contribution of it for such patients to survive but at the same time, there are lot of other issues related to this disease due to its chronic and life-threatening nature. One of the main issues that might be provoked due to thalassemia is Psychological distress which is due to the chronic nature and its persistent/ invasive procedures for treatment and this is eventually a biggest challenge for such patients. Such Psychological issues not only adversely affect the social life of the patients' but it may also hamper the medical treatment of the patients. As hope and will-power is essential for better cure (Origa, 2017).

The issues related to the nature of this disease such as hereditary, the outbreak of the disease in the inception of the life's span, abnormality in appearance and deformity, the fear of premature death and the requirement of persistent treatment bring about many negative effects on these patients. These adolescent patients are in distress and anxiety related to inferiority, apprehension, fear, despair and hopelessness. History is evident that there is an impactful relationship of chronic illness and mental health diseases and this also depicts that thalassemia is unexceptionally contributed towards mental health issues (Miri et al., 2013).

Gotay et al., in 1992, defined Psychological Wellbeing to be a state of wellbeing with that being said is composition of 2 elements, with the capability to accomplish activities taking place on daily basis that also reflect the psychological and physical needs, also social security and contentment including health and levels of functioning.

Psychological Wellbeing is "a multidimensional concept that refers to an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, and standards". It is

influenced by a variety of variables, including an individual's overall mental and physical health which is why it is adequate to consider these factors when assessing it. Physical health, psychological state, level of autonomy, social relationships, beliefs, and relationship to salient features of the environment etc. should therefore be considered in the assessment. This might be due to the fact that with increasing the intensity of a life-threatening disease like thalassemia, emotional sensitivity also increases. This proportional relationship maybe because of hopelessness, increase in risk of related diseases and the constant strain and stressors of providing or maintain a quality standard of living for their loved ones. Other reasons specific to Pakistani culture may include anxiety, societal pressures, financial instability, death of a family member, loved one and psychological problems. As compared to younger age groups, with age responsibilities also increase. The younger age group has, comparatively, far lesser responsibilities resting on their shoulders since the younger generation is accommodated, supported and financed by their parents/guardians. It is also important to factor in the socioeconomic aspect of the various domains of life that significantly correlate to the Pakistani population. Higher socioeconomic status is related to a better mental health. Pakistan being a developing nation, the community members with a low socioeconomic background are more vulnerable and are more likely to report in reduced mental health.

In recent years, the role of psychological well-being in psychological health has received further attention. Mental well-being is the consequence of a grouping of emotional adjustment, personality traits, identity, and life experiences. Ryff (1995) considers psychological well-being as an emotional health which is the state of being aware of the wholeness and integrity of all existing beings. It has six components including self-acceptance (the ability to observe and accept personal weaknesses and strengths), purposefulness (having motives and goals that give direction and meaning to one's life), personal development (feeling that potential talents and abilities will be activated over time), positive relationship with others (having intimate and valuable relationship with important people in life), environmental control (the ability to adjust and control living issues especially daily life) and autonomy (the ability to pursuit wishes and practice

accordingly based on personal principles even if they are against the social law and tradition).

Due to fact that thalassemia major is the most common hereditary anemia in many countries of the world and few studies are available on the different psychiatric aspects of this disease and the counseling psychiatric and social needs of these patients, it is significant to investigate the effect of psychological therapies in reducing the symptoms of thalassemia major (Rezaei et al., 2015).

An essential human ability to successfully adapt to risk factors is resilience. In medicine and psychology, resilience is defined as physical resistance and spontaneous recovery and the ability to re-establish emotional balance in stressful situations; resilience refers to features that participate in improving speed and rate of recovery after confronting stress. Resilience also refers to the dynamic process of adapting positively to bitter and disastrous experiences (Moorjani et al., 2006).

Campbell-Sills and her colleagues in 2006 quoted works of developmental psychologists that describe the construct of resilience as vital process that lets people to demonstrate positive adaptation when experienced with adversity or a traumatizing event. However, they speak of the essence of resilience to be the ability or the capacity for an individual to recover from stress effectively and continue with their normal functioning despite what they've gone through. Empirical studies have shown that resilience has a negative association with negative mental health indicators and enjoys a positive correlation with positive indicators of mental health (Hu et al., 2015).

Satici in 2016 found that resilience, through the role of mediating hope, is able to predict subjective wellbeing and Vitale in 2015 discovered the vital role resilience plays in contributing to positive outcomes for life satisfaction which was indicated in his study with individuals with past childhood trauma. Smith in 2009 investigated the correlation between resilience and good emotion and he discovered a positive association between the two.

An important aspect in identifying a person's mental wellbeing is resilience. It can be viewed as a personality attribute, a practical, distinctive trait of a person which alleviates the harmful impact of stress and curtails depressive symptoms. Resilience is also envisaged as technique which involves positive outcomes when faced with adversity. It's also conceded as the ability to manage substantial

changes, rebound when faced with adversity and unpredictability. This innate ability expands in capacity throughout years and through experiences. Individuals with high resilience indicate lower levels of avoidance that enable them cope with complications caused by illnesses and they do not have tendency to make illness look disastrous. Studies have shown that resilience has a positive relationship with social interaction, optimism, power, and functional independence, in contrast to negative correlation and sympathy with a range of psychological and physical pressures such as depression symptoms, post-traumatic stress disorder and physical disability. (Parviniannasab et al., 2020). The relationships between Resilience, Psychological Wellbeing and Coping Skills indicators have differed across studies. Numerous researchers have conducted evaluations to condense the study results (Davydov, 2010). Although, the researchers have recognized this relationship in part but these declarative views tend to possess limitation for instance the reviews cannot be made reliable or can be guaranteed simply on the basis of convenience sampling or emphasize on statistical significance not unless the sample size is examined. Otherwise, it becomes increasingly difficult to achieve an adequate apprehension of the correlation between Stress Management, Resilience and Psychological Wellbeing.

## **METHODOLOGY**

### **1.1 Sample**

The statistical population of this study included adolescent patients age ranging from 13 to 18 years with thalassemia major. According to the method of sample size determination in behavioral studies, a minimum sample size of 134 patients is determined for this research through  $G^*$  power, with effect size 4, probability of error .05 and power .95 (Faul et al, 2007).

### **1.2 Research Design**

This is cross-sectional study that was conducted on thalassemia centers for collection of data. This study is quantitative and correlational approach to examine the relationship between three variables.

### **1.3 Measures**

The data for this study was collected by using Demographic Sheet, Jalowiec Coping Scale (JCS),

Connor-Davidson Resilience Scale (CD-RISC) and Ryff Scale of Psychological Well-Being (RSPWB).

#### **i. Demographic Questionnaire**

Demographic information sheet comprises of information on gender, age, level of education, blood transfusion frequency on monthly basis, family income, bone marrow transplantation and splenectomy history.

#### **ii. The Connor-Davidson Resilience Scale**

CD-RISC is a test which consists of 25 items and these items are measuring the person's ability to manage the stress and adversity in past few months. Likert Scale having 5-points ranging from 0 (not true at all) to 4 (nearly true all of the time) is used for scoring. The Connor-Davidson Resilience Scale (CD-RISC) was developed by Kathryn M. Connor and Jonathan R.T. Davidson as a means of assessing resilience. The CD-RISC is based on Connor and Davidson's operational definition of resilience, which is the ability to "thrive in the face of adversity." Since its development in 2003, the CD-RISC has been tested in several contexts with a variety of populations. The total score is from 0 to 100 in which greater score depicts higher resilience level. Internal consistency of the scale was reported as 0.89 whereas reliability of test-retest for subscales of coping style was 0.87.

#### **iii. Jalowiec Coping Scale**

JCS is derived from the research of Lazarus and Folkman (1984) and it consists of 60 items divided into eight subscales: confrontive (10 items), evasive (13 items), optimistic (9 items), fatalistic (4 items), emotive (5 items), palliative (7 items), supportive (5 items) and self-reliant (7 items).

Only the sub - dimensions of confrontive, optimistic, supportive (as courageous ability to cope), evasive, and emotive (as defensive having to cope) will be used in the RIM model in the current study. Each of these items is scored on a four-point Likert scale ranging from 0 (never used) to 3 (often used). Higher scores indicate greater use of all of the coping styles mentioned above. Internal consistency of the JCS was reported as 0.89 whereas reliability of test-retest for subscales of coping style was ranged from 0.81 to 0.86.

**iv. Psychological Well-Being Scale**

RSPWB was developed by Ryff & Keyes in 1995. The original form of the scale had 120 questions, but shorter formats of 84, 54, and 18 questions were later developed and evaluated. The scale has six subscales of self-acceptance, positive relationship with others, autonomy, environmental control, personal development, and purposeful life. Shorter scale of 18 items will be used in this study. The reliability coefficient of this tool was reported by Reef and Keys between 0.83 and 0.91 and its reliability was 0.85 in a Khodabakhsh and Mansouri study, (2022).

**1.4 Inclusion Criteria**

The inclusion criteria for this study are:

- (1) Participants age should be between the age bracket of 13 and 18 years.
- (2) Participants having confirmation of beta-thalassemia major diagnosis which can be verified by Electrophoresis of Hemoglobin.
- (3) The participants should have reading and writing skills in Urdu/English language.
- (4) They should have willingness to participate.

**1.5 Exclusion Criteria**

Exclusion criteria for this study are

- (1) Participants whose age is less than 13 and greater than 18 years are excluded.
- (2) Legal guardian or child Refusal to participate in this study.
- (3) Unwillingness to participate
- (4) Illiterate or unable to read or understand the survey questions.

**1.6 Research Procedure**

The research was carried out using purposive random sampling from various thalassemia centers of

Karachi. Participants will be informed of the purpose and significance of the study.

The selected sample will complete the prep form of demographic information (age, gender, education) as well as coping, resilience and wellbeing scales.

**1.7 Ethical considerations**

To observe ethical principles, individuals were briefed about the purpose of the research and informed consent was taken by the participants. They were also be enlightened that the information, irrespective to the names of individuals, obtained from this study will be kept completely confidential and data will be shared in research anonymously. Participants were also be briefed that they had right to withdraw from data collection procedure at any time, if they feel any kind of difficulty or reservation.

**1.8 Data Analysis**

The SPSS software (version 22.0) was used to analyze the data. Participants' demographic data was examined utilizing descriptive statistics such as frequency and percentage. Pearson product moment coefficient of correlation will be analyzed for understanding the relationship of coping strategies and psychological well-being and the mediating impact of resilience will be analyzed through Process and Hayes.

**RESULTS AND DISCUSSION**

The mean ± SD of the participants' age was 16.28 ± 2.57 years old. The sample included 134 adolescents (78 boys and 56 girls) aged between 11 and 21 years old. Most of the participants were Below Diploma (n = 67, 50%) in age range of 15–17 years old (41%). A total of 62 adolescents (46.3%) were referred for blood transfusion every month.

**TABLE 1 Demographic characteristics of the participants (N = 134)**

Variables	Frequency	Percentage (%)
<b>Age (year)</b>		
11–14	38	28.4
15–17	55	41
18–21	41	30.6
<b>Gender</b>		
Male	78	58.2
Female	56	41.8



Education Level		
Illiterate	2	1.5
Below diploma	67	50
Diploma	35	26.1
Academic degree	30	22.4

  

Splenectomy		
Yes	27	20.14
No	107	79.86

  

Frequency of transfusion		
2 weeks or less	57	42.5
3 weeks	62	46.3
4 weeks or more	15	11.2

Most of the male subjects had higher mean scores on Courageous Coping (M = 47.50, SD= 10.46) compared to the female ones (M = 46.23, SD= 9.06). Most of the male subjects also had higher mean scores on the Resilience Scale (M = 56.08, SD= 20.72) compared to the female ones (M = 53.80, SD= 16.71). Four of the five bivariate correlations between coping strategies subscales (confrontative, optimistic, supportant,

and evasive) and resilience were positive and significant at the ( $p < .001$ ) level, whereas a not significant negative relationship was found between the remaining one (emotive) and resilience ( $p > .05$ ). The bivariate correlations between courageous coping and resilience ( $r = .59$ ) was significant, while this correlations between defensive coping and resilience ( $r = .19$ ) was not significant ( $p > .05$ ).

**TABLE 2** Mean and SD of courageous coping, defensive coping and resilience in the studied units based on gender:

Variables	Female	Male	p Value
<b>Courageous Coping</b>	46.23 ± 9.06	47.50 ± 10.46	.50
Confrontive	20.32 ± 5.07	20.76 ± 5.42	.29
Optimistic	18.23 ± 4.72	18.91 ± 4.9	.42
Supportant	7.67 ± 2.69	7.82 ± 3.48	.79
<b>Defensive Coping</b>	28.50 ± 7.23	28.87 ± 9.06	.79
Evasive	21.01 ± 5.20	22.05 ± 6.31	.30
Resilience	53.80 ± 16.71	56.08 ± 20.72	.28

The regression equation with all five coping subscales (confrontative, optimistic, supportant, emotive, and evasive) as predictors were significantly related to the resilience scale,  $R^2 = .38$ , adjusted  $R^2 = .35$ ,  $F(5, 128) = 15.28$ ,  $p < .05$ ).

Approximately 38% of changes in resilience scale were explained by the composition of the five coping subscales with a level of contribution of each predictor to be  $\beta = .40$  by Optimistic,  $\beta = .22$  by Confrontive,  $\beta = .11$  by Supportive,  $\beta = .10$  by Evasive, and  $\beta = -.07$  by Emotive.

**TABLE 3** The relationship between Resilience with five subscales of Coping Strategy

	Courageous coping subscales		Defensive coping subscales		
	Confrontive	Optimistic	Supportant	Evasive	Emotive
Resilience	<i>r</i> .41	.55	.32	.28	.009
	<i>P</i> <sup>a</sup> <.001	<.001	<.001	<.001	.916

<sup>a</sup> Pearson correlation coefficient test

**TABLE 4** Regression model for Predictor variable of the Resilience

Dependent variable	Predictors variable	B	SE	Beta	t	p Value <sup>a</sup>
Resilience	Confrontive	.811	0.277	0.224	2.933	.004
	Optimistic	1.562	0.329	0.394	4.748	.000
	Supportant	.674	0.473	0.112	1.426	.156
	Evasive	.346	0.297	0.106	1.167	.245
	Emotive	.392	0.461	-0.074	-0.852	.396

Note: R<sup>2</sup> = .38, adjusted R<sup>2</sup> = .35, F (5, 128) = 15.28, p < .05.

<sup>a</sup> Linear regression

According to the data collection and findings, the overall mean scores of subscales related to courageous coping namely confrontive, optimistic and supportant were showing slightly higher trend in boys as compared to girls. However, the data findings relevant to the coping strategies do not show any significant difference between courageous coping and gender, these results are consistent with the previous studies results in which boys' trend is showing to use active coping usage as compared to girls (Bazrafshan et al., 2014). Similarly, the overall means score of subscales related to defensive coping namely emotive and evasive were also higher slightly in boys. Consequently, this difference in mean scores can be contributed to the difference in scores of evasive coping which was showing higher trend in boys and it showed that boys were using evasive coping strategies which includes self-blame and substance abuse as compared to girls (Kim et al., 2017).

In contrast to the findings of this study, the other studies results depicted that evasive coping strategy was greater in female as compared to male subjects. At the same time, the emotive coping subscales scores were lower in girls as compared to boys which is same as previous studies (Howerton & Van Gundy, 2009; Kim et al., 2017). The results of this study showed that there a significant positive correlation between resilience and the courageous coping subscales namely confrontive, supportive and optimism. Consequently, this positive correlation

between resilience and courageous coping enhances the Psychological well-being which is showed in results. These results are in line with the RIM (Resilience in Illness) model and other studies (Chen et al., 2018; Thompson et al., 2018). Correlation for subscales of optimism was also high as compared to other subscales. The same results for optimism were showed in previous studies as well and consequently, resilience is considered as an integral part for enhancing optimism. This also depicted the mediating role of resilience in the relationship of coping strategies and psychological well-being (Parviniannasab et al., 2020).

Resilience is basically such type of variable which is context-based and very much dependent upon the culture. This might be affected by various social and environmental factors. Overall, the current study specifies the role of resilience in the relationship of coping strategies and psychological well-being as explained by Haase et al., (2014) among adolescent cancer patients which indicated that active coping strategies or problem-focused coping is related to positive outcome adaptation (resilience). This study also supported the previous study findings that indicated that lower resilience levels may lead to emotive and evasive coping strategies (Messinger, 2017).

The results of this study showed that mediating effect of resilience on coping mechanism is effective and it not only develops self-acceptance, autonomy, purposeful life, personal development, positive

relationship with others but it also refines psychological wellbeing of the person but it has less effect on environmental control as shown by the results. It is worthwhile to mention over here that the findings of this study are also comply with the Hashem Zehi et al., (2016) study in which they also mentioned the same relationship of coping strategies and its impact on psychological wellbeing of thalassemic patients. Similarly, the same phenomena were also discussed in Antoni et al., (2001) study in which they reported the relationship of resilience and stress coping in improving the psychological wellbeing of chronic diseases. As far as the conditions of the disease is concerned and limitations of that disease that may increase the feeling of despair and hopelessness in patient, it is the resilience that actually enhances the tolerance level in such tough situations and enables a patient to combat with such feelings of hopelessness. Resilience not only encompasses a person's mental and inner ability to uphold the tough situations of stress in such a way that a person is able to balance those conditions but it may also enhance his/her feelings of hope and optimism (Duffy et al., 2010) which eventually the one main reason that show the effectiveness of resilience in enhancing the psychological wellbeing in return.

The current study also revealed some interesting facts related to the gender of the adolescent thalassemic patients. These findings revealed that male adolescents have more emotional and physical problems as compared to the girls. One of the reasons is cultural differences and in Pakistani society, the medical issues of male children are more highlighted as compared to girls. Similarly, the parents are more concerned for the male child treatment as compared to the female child issues. The same phenomena were also discussed in previous researches as well in which male children having thalassemia and hemophilia diseases are showing more physical and emotional health problems in comparison of female children (Borgna-Pignatti, Marsella, & Pepe, 2010). For improving the psychological conditions of the adolescent thalassemic patients, it is very necessary that an intervention plan must be implemented. This intervention plan comprises of such useful trainings that may enhance the resilience and coping ability of such patients. This can be done by adopting such trainings and strategies that give awareness to such patients about stress management, problem solving mechanisms, self-expression, anger management,

self-management and mental relaxation. These stress management and resilience trainings (SMART) have positive impact on the mental health of thalassemic patients and it may promote the psychological wellbeing of such patients. Interventions related to social support may also be used as an effective tool for establishing the rehabilitation avenues for such adolescents thalassemic patients.

## CONCLUSION

The findings and analysis of the data in the current study revealed that resilience plays a vital role as mediator in the relationship of coping strategies and psychological wellbeing of thalassemic adolescent patients. The study further suggested that various factors like courageous coping as protective factors and defensive coping as risk factors affects resilience. Therefore, keeping in view the role and importance of these factors in estimating the psychological wellbeing of thalassemic patients has impactful contribution in planning and implementing effective plans for interventions to enhance resilience and coping strategies of such patients in order to maximize their psychological wellbeing.

## REFERENCES

- Abd-Elmawla, M. A., Rizk, S. M., Youssry, I., & Shaheen, A. A. (2016). Impact of Genetic Polymorphism of methylenetetrahydrofolate reductase C677T on Development of Hyperhomocysteinemia and Related Oxidative Changes in Egyptian  $\beta$ -Thalassemia Major Patients, 11(5), e0155070.
- Agapidou, A., Vlachaki, E., Theodoridis, T., Economou, M., & Perifanis, V. (2013). Cyclosporine therapy during pregnancy in a patient with  $\beta$ -thalassemia major and autoimmune haemolytic anemia: a case report and review of the literature. *Hippokratia*, 17(1), 85–87.
- Ahern, N. R., Ark, P., & Byers, J. (2008). Resilience and coping strategies in adolescents. *Paediatric Nursing*, 20(10), 32–37. <https://doi.org/10.7748/paed2008.12.20.10.32.c6903>
- Antoni MH, Lehman JM, Kilbourn KM (2001), Cognitive-behavioral stress management intervention decreases the prevalence of depression and enhances benefit finding among women under treatment for early-stage breast cancer. *Health Psychology* 20(1): 20-32.
- Aydinok, Y., Bukusoglu, N., Eremis, S., Solak, U., & Yilmaz, D. (2004). Psychosocial implications of Thalassemia Major. *Pediatrics International*, 47(1), 84-89.
- Bazrafshan, M.-R., Jahangir, F., Mansouri, A., & Kashfi, S. H. (2014). Coping strategies in people attempting

- suicide. *International Journal of High Risk Behaviors & Addiction*, 3(1), 16265.
- Beck, A. T., Freeman, A., and Associates. (1990). *Cognitive therapy of personality disorders*. New York, NY: Guilford Press.
- Campbell-Sills L, Cohan SL, Stein MB. Relationship of resilience to personality, coping, and psychiatric symptoms in young adults. *Behavioral and Resilience Therapy*. (2006); 44(4):585–99.
- Chen, K.-J., Yang, C.-C., & Chiang, H.-H. (2018). Model of coping strategies, resilience, psychological well-being, and perceived health among military personnel. *Journal of Medical Sciences*, 38(2), 73–80.
- Connor KM, Sutherland SM, Tupler LA, Churchill LE, Malik ML, Davidson JRT. (1999). Fluoxetine in posttraumatic stress disorder: a randomized, placebo-controlled trial. *British Journal of Psychology* 175:17–22.
- Cronbach, L. J. (1950). Further Evidence on Response Sets and Test Design. *Educational and Psychological Measurement*, 10, 3-31.
- Davydov, D. M., Stewart, R., Ritchie, K., & Chaudieu, I. (2010). Resilience and mental health. *Clinical Psychology Review*, 30, 479-495.
- Duffy James D, Valentine Alan D (2010). *Therapeutic relationship MD Anderson manual of psychosocial oncology*; New York: Hill Company.
- Ghasemi, A., Keikhaei, B., & Ghodsi, R. (2014). Side effects of hydroxyurea in patients with Thalassemia major and thalassemia intermedia and sickle cell anemia. *Iranian journal of pediatric hematology and oncology*, 4(3), 114–117.
- Gotay CC, Korn EL, McCabe MS, Moore TD, Cheson BD. (1992); Quality-of-life assessment in cancer treatment protocols, research issues in protocol development; *Journal of Netherlands Cancer Institute*.
- Haase, D., Larondelle, N., Andersson, E. (2014): A Quantitative Review of Urban Ecosystem Service Assessments: Concepts, Models, and Implementation. *AMBIO* 43, 413–433.
- Hashem-Zahi S. (2016), The Effectiveness of Cognitive Behavioral Therapy on Anxiety and Quality of Life among Thalassemia Patients in Major City. Sistan and Baluchistan: University of Sistan and Baluchistan
- Howerton, A., & Van Gundy, K. (2009). Sex differences in coping styles and implications for depressed mood. *International journal of stress management*, 16(4), 333–350.
- Hu, T., Zhang, D., & Wang, J. (2015). A meta-analysis of the trait resilience and mental health. *Personality and Individual Differences*, 76, 18-27.
- Kim, J. E., Song, I. H., & Lee, S.-H. (2017). Gender differences of stressful life events, coping style, symptom severity, and health-related quality of life in patients with panic disorder. *The Journal of Nervous and Mental Disease*, 205(9), 714–719
- Kosaryan, M., Karami, H., Darvishi-Khezri, H., Akbarzadeh, R., Aliasgharian, A., & Bromand, K. (2019). Treatment status of patients with B-Thalassemia Major in Northern Iran: Thalassemia Registry System. *Iranian Journal of Public Health*, 48(7), 1335–1345.
- Lamki Z, Saadon M, Wasifuddin SM, Wali Y, Wafa B, Maawaly N. (2006): The impact of living with thalassemia major on affected child, parents and siblings. *International Conference for Thalassemia patients and parents*.
- Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping*. Springer Publishing Company.
- Liu, Ben-Chieh. (1976). Quality of life indicators in U.S. metropolitan areas: a statistical analysis
- Messinger, D. L. (2017). *Resilience and Coping in the Adolescent and Young Adult with Type 1 Diabetes*. (PhD). Seton Hall University, Doctor of Philosophy Department of Nursing.
- Miri, M., Tabrizi Namini, M., Hadipour Dehshal, M., Sadeghian Varnosfaderani, F., Ahmadvand, A., Yousefi Darestani, S., & Manshadi, M. (2013). Thalassemia in Iran in last twenty years: The carrier rates and the births trend. *Iranian Journal of Blood and Cancer*, 6(1), 11–17.
- Mirza A, Ghani A, Pal A, Sami A, Hannan S, Ashraf Z, Iqbal S, Malik UZ, Hayat U, Fatmi Z. (2013); Thalassemia and premarital screening: potential for implementation of a screening program among young people in Pakistan. *Hemoglobin*;37(2):160-70.
- Moorjani JD, Issac C. (2006), Neurotic manifestations in adolescents with thalassemia major. *Indian Journal of Pediatrics*, 73:603–607.
- Origa R. (2017).  $\beta$ -Thalassemia. Genetics in medicine: *official journal of the American College of Medical Genetics*, 19(6), 609–619.
- Parker JS, Benson MJ. (2004), Parent-adolescent relations and adolescent functioning: self-esteem, substance abuse and delinquency. *Adolescence*; 39:519–530.
- Parviniannasab, A. M., Rakhshan, M., Momennasab, M., Soltanian, M., Rambod, M., & Akbarzadeh, M. (2020). Haemophilic adolescents' perspectives of resilience: A qualitative study based on the resilience in illness model. *Clinical Child Psychology and Psychiatry*, 25(2), 346–358.
- Rezaei, N., Naderimaghani, S., Ghasemian, A., Moghaddam, S. S., Zareiy, S., Sobhani, S., & Kompani, F. (2015). Burden of hemoglobinopathies (thalassemia, sickle cell disorders and G6PD deficiency) in Iran, 1990–2010: Findings from the



- Global Burden of Disease Study 2010. *Archives of Iranian Medicine*, 18(8), 502–507.
- Rosenberg, A. R., Yi-Frazier, J. P., Eaton, L., Wharton, C., Cochrane, K., Pihoker, C., Baker, K. S., & McCauley, E. (2015). Promoting resilience in stress management: A pilot study of a novel resilience-promoting intervention for adolescents and young adults with serious illness. *Journal of Pediatric Psychology*, 40(9), 992–999.
- Ryff CD, Keyes CL. The structure of psychological well-being revisited. *Journal of Perspectives of Social Psychology*, 1995; 69(4): 719-27.
- Saini A, Chandra J, Goswami U, Singh V, Dutta AK. (2007), Case control study of psychosocial morbidity in beta thalassemia major. *Journal of Pediatrician*, 150:516–520.
- Satici, S. A. (2016). Psychological vulnerability, resilience, and subjective well-being: the mediating role of hope. *Personality and Individual Differences*, 102, 68–73. doi: 10.1016/j.paid.2016.06.057
- Smith, B. W., Dalen, J., Wiggins, K., Tooley, E., Christopher, P., & Bernard, J. (2008). The Brief Resilience Scale: Assessing the Ability to Bounce Back. *International Journal of Behavioral Medicine*, 15, 194-200.
- Smith, P. R. (2009). Resilience: resistance factor for depressive symptom. *Journal of Psychiatry and Mental Health Nursing*, 16, 829–837. doi: 10.1111/j.1365-2850.2009.01463
- Telfer P, Constantinidou G, Andreou P, Christou S, Modell B, Angastiniotis Medicine, Quality of life in thalassemia. *Ann N Y Acad Sci* 2005; 1054:273–282.
- Thompson, N. J., Fiorillo, D., Rothbaum, B. O., Ressler, K. J., & Michopoulos, V. (2018). Coping strategies as mediators in relation to resilience and posttraumatic stress disorder. *Journal of Affective Disorders*, 225, 153–159.
- Tusaie, K., Puskar, K., & Sereika, S. M. (2007). A predictive and moderating model of psychosocial resilience in adolescents. *Journal of Nursing Scholarship*, 39(1), 54–60. <https://doi.org/10.1111/j.1547-5069.2007.00143>.

