

## **Illness Perception and Coping as Predictors of Quality of Life in Adolescents with Beta Thalassemia**

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**Abstract:** Thalassemia involves the absence of genes that affects the body's ability to produce a protein in the red blood cells called hemoglobin (George & Tan, 2010). The objective of the present study is to explore whether there are gender differences in illness perception, coping, quality of life and their dimensions in adolescents with beta thalassemia. This study also aims to find whether illness perception and coping predicts quality of life in adolescents with beta thalassemia. A non-probability purposive sampling technique was used to select a sample of 100 adolescents with beta thalassemia (56 boys and 44 girls). The results of the study revealed that the main predictors of quality of life in boys were the acceptance, use of emotional support, humour, and self-distraction dimensions of coping; and illness perception and its identity dimension ( $p < 0.05$ ). The main predictors of quality of life in girls were the planning, behavioral disengagement, humor, venting, acceptance, self-distraction, and active coping dimensions of coping; and the consequences, illness concern, identity, treatment control, coherence, and personal control dimensions of illness perception ( $p < 0.05$ ). However, no gender differences were found in illness perception, coping, and quality of life in patients with beta thalassemia ( $p > 0.05$ ). Since this disorder poses great challenges to the patients and their family members, inculcating constructive coping strategies in their daily activities will enhance physical, emotional, cognitive functioning and normal psychosocial life. Furthermore, conducting genetic counseling and prenatal screening will help decrease the prevalence of the illness.

**Keywords:** Adolescence, Caregivers, Coping styles, Illness perception, Thalassemia, Quality of life

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### **I. INTRODUCTION**

Thalassemia is the most common human inherited blood and hemoglobin disorders. According to the Cooley's anaemia Foundation (1957), "thalassemia is a blood disorder passed down through families (inherited) in which the body makes an abnormal form of hemoglobin. Thalassemia Major or Cooley's Anaemia is the most severe form of beta thalassemia in which the complete lack of beta protein in the hemoglobin causes a life-threatening anemia that requires regular blood transfusions and extensive ongoing medical care".

The disorder poses great challenges to the patients, and their family members at the physical, emotional, and cognitive levels causing disruption to their normal psychosocial life (Wahab et al., 2011). A study conducted by Khurana et al. (2006) reported that thalassemia affected the domains of education (70%) and sports (72%). The individuals were also dissatisfied with their body image. The adolescents were anxious about their future health and education. The same study found that there was an increase in the psychosocial burden that was perceived by the affected adolescents.

Studies in primary health care focus on the importance of the patient's beliefs and emotional responses to their illness in considering their satisfaction with the consultation, testing, and future health care use (Petrie et al., 2007). According to Cavelti (2012), illness perception is defined as "the beliefs a patient holds about his/her health problems, has been shown to affect coping in the context of a physical or mental illness." The perceptions of the patient about their illness have also been associated with treatment adherence and functional recovery (Petrie et al., 2007).

Hussian et al. (2008) conducted a study on the relationship between anxiety, depression, and illness perception in 108 tuberculosis patients in Pakistan. The study found that half of the patients met the criteria for probable depression and anxiety. Negative illness perceptions were related to mood symptoms. Hence, increased depression and anxiety scores were a result of tuberculosis symptoms, and more perceived consequence of the illness along with less control over the illness. Most of these studies have been conducted from a perspective of a theoretical framework called as the Self-Regulation Model (SRM) of health and illness (Leventhal et al.,

1992). According to this model, patients make sense of their experiences and provide a basis for their coping resources by constructing their own representations or models.

The presence of beta thalassemia in a family member can cause clinical and psychological challenges in all the family members and thus coping strategies are required. Coping is the process by which people try to manage the perceived discrepancy between the demands and resources they appraise in a stressful situation. Although coping efforts can be aimed at correcting or mastering the problem, they may also simply help the person alter his or her perception of a discrepancy, tolerate or accept the harm or threat, or escape or avoid the situation (Lazarus & Folkman, 1984; Carver & Connor-Smith, 2010). There is growing evidence on the ways of coping and its effects on the mental health as well as the physical and social well-being (Wheaton, 1985). Age and gender are some of the factors that affect the coping health interactions (Feldman, Fisher, Ransom, & Dimiceli, 1995).

Emotion-focused coping aims at controlling or regulating their emotional responses to a stressful situation. Problem-focused coping aims at reducing the demands of the stressful situation or expanding the resources to deal with the situation (Lazarus & Folkman, 1984). A study conducted by Hashemi et al. (2015) on 87 adolescents with beta thalassemia revealed that there was an increase in the problem-focused coping strategies in experimental group in one month and two months after the intervention. The results suggested that teaching coping strategies can lead to improved use of problem-focused coping strategies and thereby effective coping with stress in patients with beta thalassemia.

Quality of life is another important factor in chronic illness. The World Health Organization (WHOQOL Group, 1993) defined the quality of life as: 'An individual 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, standards and concerns.' Another study was done by Campbell et al. (2006) in Malaysia on the health-related quality of life of children with thalassemia. The findings reported that thalassemia had a negative impact on the physical, emotional, social, and school functioning of the patients. Quality of life (QOL) has become a major area for multidisciplinary research for a variety of reasons. As Boiniet al.(2004) put it, 'Physicians now have the opportunity to add life to years, as well as adding years to life.' There are many factors that are shown to affect the Quality of Life of a patient, namely, the age of the patient, the culture in which one lives, the aspects of one's illness, the aspects of one's treatment, and the psychosocial influences on the quality of life of the patient. Quality of life, thus, can be an important index of effective health care (Wahab et al., 2011).

Thalassemia and abnormal hemoglobin have the treatment of regular blood transfusion and iron chelation. In the last 20 years, there has been progress in relation to the diagnosis, prevention, and management of thalassemia (Olivieri & Brittenham, 2013). To the best of the researcher's knowledge, illness perception, coping, and quality of life have not been studied together on patients with beta thalassemia and it will add to the existing knowledge on the various aspects of health of children suffering from beta thalassemia. In this context, the objectives of the present research are as follows:

## II. RESEARCH OBJECTIVES

1. To examine whether illness perception and its 8 dimensions (viz., consequences, timeline, personal control, treatment control, identity, coherence, emotional representation, and illness concern) and coping, measured in terms of its 14 dimensions (viz., self-distraction, active coping, denial, substance use, use of emotional support, use of instrumental support, behavioral disengagement, venting, positive reframing, planning, humor, acceptance, religion, and self-blame) predict quality of life and its 4 dimensions (viz., physical functioning, psychological functioning, social functioning, and environment) in adolescent boys and girls with beta thalassemia.
2. To study whether there is any gender difference in participants with beta thalassemia with respect to illness perception, coping and quality of life.

## III. METHOD

### Research Design

The present study adopts a correlational design to determine whether illness perception and coping predict quality of life in adolescent boys and girls with beta thalassemia. This study also adopts a between-group design to determine whether there are any gender differences in patients with beta thalassemia with respect to illness perception, coping, quality of life and their dimensions.

### Sample

A non-probability purposive sampling technique was used to select a sample of 100 individuals, aged 10 – 18 years, with beta thalassemia. Out of them, 56 were adolescent boys and 44 were adolescent girls. Individuals who had received at least 15 blood transfusions in a year were included in this sample. Patients suffering from alpha thalassemia or having any comorbid condition such as HCV, HIV/AIDS, and diabetes were not included in this sample.

**Instruments**

**1. Information schedule:**

The patients were first asked to fill up a socio demographic sheet which included details like their name, age, sex, mother tongue, religion, relationship status, educational qualifications, per monthly income, family type, number of siblings, and the like in writing, on the information schedule.

**2. The Brief Illness Perception Questionnaire (Brief IPQ):**

The Brief Illness Perception Questionnaire (Brief IPQ) was developed by Broadbent et al. (2006). It is a 9 item questionnaire designed to rapidly assess cognitive and emotional representations of illness (Broadbent et al., 2006). The dimensions of this scale are consequences, timeline, personal control, treatment control, identity, coherence, emotional representation and illness concern. To compute the score, reverse score items 3, 4, and 7 and add these to items 1, 2, 5, 6, and 8. A higher score reflects a more threatening view of the illness.

Good test-retest reliability (Pearson correlations 0.24–0.73) has been demonstrated for the scale (Broadbent et al., 2006). Equivalent scales of the brief IPQ and IPQ-R has moderate to good correlations when tested for concurrent validity (Pearson correlations 0.32–0.63) (Broadbent et al., 2006).

**3. The Brief Cope Scale- Carver (1997):**

The Brief COPE was originally developed by Carver (1997) and translated into Urdu by Akhtar (2005). Brief COPE is a brief form of COPE Inventory (Carver et al., 1989) consisting of 28 items, categorized into 14 dimensions. The dimensions are self-distraction, active coping, denial, substance use, use of emotional support, use of instrumental support, behavioral disengagement, venting, positive reframing, planning, humor, acceptance, religion and self-blame. Items are arranged in a 4-point Likert format (1= Never, 2= Very less, 3= Sometimes and 4= A lot). The items are summed for each subsection separately to get a total score on all 14 dimensions. The higher the score on each subscale indicate more use of that particular coping strategy and low score indicate less use of that coping strategy. There is no reverse scoring. Internal consistencies for the scale ranged from 0.25 to 1.00. Meanwhile, the Intraclass Correlation Coefficient (ICC) ranged from 0.05 to 1.00.

**4. The Quality of Life questionnaire (WHOQOL- BREF) - WHOQOL Group (2003):**

The scale was originally developed by World Health Organization in 2003 and then adapted and translated into Urdu language in 2003 by Khan, Akhtar, Ayub, Alam and Laghari. It is rated on a 5-point (1-5) Likert scale. The four dimensions of the scale are physical functioning, psychological functioning, social functioning and environment.

The scores on each dimension of the scale are scaled in positive direction i.e., high score represents high Quality of Life. The overall score ranges from 24-120. The mean score of items within each dimension is used to calculate the domain score. The scale has a test-retest reliability of 0.80.

**IV. RESULTS**

**Table 1**–Summary of stepwise regression, showing predictors of Quality of Life and its dimensions in adolescent boys with beta thalassemia: Total Quality of Life, Quality of Life Physical Functioning, Quality of Life Psychological Functioning, Quality of Life Social Functioning, and Environment (N=56)

Criterion Variable	Changes in R square												Total Adjusted R square
	BC Acceptance	BC Use of Emotional sup	Total sup/BIP	BIP Identity	BC Humor	BC Self Distraction	BC Acceptance	BC Use of Emotional Support	Total BIP	BIP Identity	BC Humor	BC Self Distraction	
Total Quality of Life	0.51**	0.33**	(-)0.23**	NS	NS	NS	0.26**	0.09**	0.05*	NS	NS	NS	0.37**
QOL Pfunctioning	0.47**	0.29**	NS	(-)0.33**	0.23*	NS	0.22**	0.07**	NS	0.11**	0.05*	NS	0.41**
QOL Psychological fr	0.57**	0.31**	NS	NS	0.23*	0.21*	0.32**	0.08**	NS	NS	0.05*	0.04*	0.46**
QOL Social functioni	NS	0.33**	NS	NS	NS	NS	NS	0.10**	NS	NS	NS	NS	0.09**
QOL Environment	0.56**	0.37**	(-)0.23**	NS	NS	NS	0.31**	0.11**	0.05*	NS	NS	NS	0.45**

Note: \*\*p<0.01; \*p<0.05

Table 1 indicates a summary of the regression analysis for quality of life and its dimensions of physical functioning, psychological functioning, social functioning, and environment. The total quality of life was predicted by the acceptance, and use of emotional support dimensions of brief cope, and the total brief illness perception. The physical functioning dimension of quality of life was predicted by the acceptance, use of emotional support, and humor dimensions of brief cope, and the identity dimension of brief illness perception. The psychological functioning dimension of quality of life was predicted by the acceptance, use of emotional support, humor, and self distraction dimensions of brief cope. The social functioning dimension of quality of life

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was predicted by the use of emotional support dimension of brief cope. The environment dimension of quality of life was predicted by the acceptance, and use of emotional support dimensions of brief cope, and the total brief illness perception.

**Table 2** -Stepwise regression analyses showing various models predicting total quality of life in adolescent boys with beta thalassemia (N=56)

Predictor	R	ΔR <sup>2</sup>	β
<u>Criterion: Total Quality of Life</u>			
Model 1	0.51	0.26**	
1. BC Acceptance			0.5**
Model 2	0.596	0.09**	
1. BC Acceptance			0.37**
2. BC Use of emotional support			0.33**
Model 3	0.639	0.05*	
1. BC Acceptance			0.37**
2. BC Use of emotional support			0.34**
3. Total BIP			(-)0.23**
Total R <sup>2</sup>			0.40**

Note: \*\*p<0.01; \*p<0.05, N= 56, β = Standardized Beta Coefficient, R = co-efficient of correlation, Δ R2 = change in R squared

A stepwise regression was performed to evaluate whether acceptance, use of emotional support and the total brief illness perception are able to predict total quality of life in adolescent boys with beta thalassemia. The contribution of acceptance dimension in predicting total quality of life was 26%. The use of emotional support dimension of brief cope was another predictor of total quality of life and its contribution in predicting total quality of life was 9%. The total brief illness perception was yet another predictor of total quality of life and contributed 5% in predicting total quality of life. The positive β value of brief cope acceptance showed a positive correlation with total quality of life (β= 0.5). The positive β value of brief cope use of emotional support showed a positive correlation with total quality of life (β= 0.33). The negative β value of total brief illness perception showed a negative correlation with total quality of life (β= -0.23).

**Table 3** -Stepwise regression analyses showing various models predicting physical functioning dimension of quality of life in adolescent boys with beta thalassemia (N=56)

Predictor	R	ΔR <sup>2</sup>	β
<u>Criterion: QOL Physical functioning</u>			
Model 1	0.471	0.22**	
1. BC Acceptance			0.47**
Model 2	0.58	0.11**	
1. BC Acceptance			0.50**
2. BIP Identity			(-)0.33**
Model 3	0.639	0.07**	
1. BC Acceptance			0.38**
2. BIP Identity			(-)0.31**
3. BC Use of Emotional Support			0.29**
Model 4	0.679	0.05*	
1. BC Acceptance			0.37**
2. BIP Identity			(-)0.28**
3. BC Use of Emotional Support			0.32**
4. BC Humor			0.23**
Total R <sup>2</sup>			0.46**

Note: \*\*p<0.01; \*p<0.05, N= 56, β = Standardized Beta Coefficient, R = co-efficient of correlation, Δ R2 = change in R squared

A stepwise regression was performed to evaluate whether acceptance, identity, use of emotional support, and humor are able to predict physical functioning dimension of quality of life in adolescent boys with beta thalassemia). The contribution of the acceptance dimension in predicting the physical functioning dimension of quality of life was 22%. Identity, use of emotional support, and humor, dimensions of brief cope

contributed 11%, 7%, and 5% respectively to the physical functioning dimension of quality of life. The positive  $\beta$  value of brief cope acceptance showed a positive correlation with quality of life physical functioning ( $\beta=0.47$ ). The negative  $\beta$  value of brief illness perception identity showed a negative correlation with the physical functioning dimension of quality of life ( $\beta= -0.33$ ). The positive  $\beta$  value of brief cope use of emotional support showed a positive correlation with the physical functioning dimension of quality of life ( $\beta= 0.29$ ). The positive  $\beta$  value of brief cope humor showed a positive correlation with the physical functioning dimension of quality of life ( $\beta= 0.23$ ).

**Table 4** -Stepwise regression analyses showing various models predicting psychological functioning dimension of quality of life in adolescent boys with beta thalassemia (N=56)

Predictor	R	$\Delta R^2$	$\beta$
<u>Criterion: QOL</u>			
<u>Psychological functioning</u>			
Model 1	0.57	0.32**	
1. BC Acceptance			0.57**
Model 2	0.637	0.08**	
1. BC Acceptance			0.44**
2. BC Use of Emotional Support			0.31**
Model 3	0.678	0.05*	
1. BC Acceptance			0.44**
2. BC Use of Emotional Support			0.34**
3. BC Humor			0.23**
Model 4	0.709	0.04*	
1. BC Acceptance			0.44**
2. BC Use of Emotional Support			0.29**
3. BC Humor			0.23**
4. BC Self Distraction			0.21**
Total R <sup>2</sup>			0.50**

Note: \*\* $p<0.01$ ; \* $p<0.05$ , N= 56,  $\beta$  = Standardized Beta Coefficient, R = co-efficient of correlation,  $\Delta R^2$  = change in R squared

A stepwise regression was performed to evaluate whether acceptance, use of emotional support, humor, and self-distraction are able to predict psychological functioning dimension of quality of life in adolescent boys with beta thalassemia. The contribution of acceptance dimension in predicting the psychological functioning dimension of quality of life was 32%. Use of emotional support, humor, and self-distraction contributed 8%, 5%, and 4% respectively to the psychological functioning dimension of quality of life. The positive  $\beta$  value of brief cope acceptance showed a positive correlation with the psychological functioning dimension of quality of life ( $\beta= 0.57$ ). The positive  $\beta$  value of brief cope use of emotional support showed a positive correlation with the psychological functioning dimension of quality of life ( $\beta= 0.31$ ). The positive  $\beta$  value of brief cope humor showed a positive correlation with the psychological functioning dimension of quality of life ( $\beta= 0.23$ ). The positive  $\beta$  value of brief cope self-distraction showed a positive correlation with the psychological functioning dimension of quality of life ( $\beta= 0.21$ ).

**Table 5** -Stepwise regression analyses showing various models predicting social functioning dimension of quality of life in adolescent boys with beta thalassemia (N=56)

Predictor	R	$\Delta R^2$	$\beta$
<u>Criterion: QOL</u>			
<u>Social Functioning</u>			
Model 1	0.33	0.10**	
1. BC Use of Emotional Support			0.33**
Total R <sup>2</sup>			0.10**

Note: \*\* $p<0.01$ ; \* $p<0.05$ , N= 56,  $\beta$  = Standardized Beta Coefficient, R = co-efficient of correlation,  $\Delta R^2$  = change in R squared

A stepwise regression was performed to evaluate whether use of emotional support is able to predict social functioning dimension of quality of life in adolescent boys with beta thalassemia. The use of emotional support dimension contributed 10% to the social functioning dimension of quality of life. The positive  $\beta$  value of brief cope use of emotional support showed a positive correlation with the social functioning dimension of quality of life ( $\beta= 0.33$ ).

**Table 6** -Stepwise regression analyses showing various models predicting environment dimension of quality of life in adolescent boys with beta thalassemia (N=56)

Predictor	R	ΔR <sup>2</sup>	β
Criterion: QOL Environment			
Model 1	0.564	0.31**	
1. BC Acceptance			0.56**
Model 2	0.66	0.11**	
1. BC Acceptance			0.41**
2. BC Use of Emotional Support			0.37**
Model 3	0.698	0.05*	
1. BC Acceptance			0.41**
2. BC Use of Emotional Support			0.38**
3. Total BIP			(-)0.23**
Total R <sup>2</sup>			0.48**

Note: \*\*p<0.01; \*p<0.05, N= 56, β = Standardized Beta Coefficient, R = co-efficient of correlation, Δ R2 = change in R squared

A stepwise regression was performed to evaluate whether acceptance, use of emotional support, and total brief illness perception are able to predict the environment dimension of quality of life in adolescent boys with beta thalassemia. The contribution of acceptance dimension of brief cope was 31% in predicting the environment dimension of quality of life. The use of emotional support dimension of brief cope contributed 11% to the environment dimension of quality of life. The total brief illness perception contributed 5% in predicting environment dimension of quality of life. The positive β value of brief cope acceptance showed a positive correlation with the environment dimension of quality of life (β= 0.56). The positive β value of brief cope use of emotional support shows a positive correlation with the environment dimension of quality of life (β= 0.37). The negative β value of total brief illness perception showed a negative correlation with the environment dimension of quality of life (β= -0.23).

**Table 7** -Summary of stepwise regression, showing predictors of Quality of Life and its dimensions in adolescent girls with beta thalassemia: Total Quality of Life, Quality of Life Physical Functioning, Quality of Life Psychological Functioning, Quality of Life Social Functioning, and Environment (N=44)

Criterion Variable □	Changes in R square																			Total Adjusted R square							
	BC	BIP	BC Behavioral	BIP InBC	BIP	BIP Treatment	BC	BC	BIP Personal	BC Self	BC Act	BIP	BC Behavioral	BIP InBC	BIP	BIP Treatment	BC Venting	BC	BIP Personal		BC Self	BC Active					
	Planning	Consequences	Disengagement	Concern	Humor	Identity	Control	Coherence	Venting	Acceptance	Control	Distraction	Coping	Planning	Consequences	Disengagement	Concern	Humor	Identity		Control	Coherence	Acceptance	Control	Distraction	Coping	
Total Quality of Life	0.49**	(-)0.30**	(-)0.34**	0.28**	0.33*	NS	NS	NS	NS	NS	NS	NS	0.24**	0.08**	0.11**	0.06**	0.07**	NS	NS	NS	NS	NS	NS	NS	NS	NS	0.52**
QOL Functioning	NS	NS	NS	NS	0.35*	(-)0.41*	(-)0.30**	0.36**	(-)0.37*	NS	NS	NS	NS	NS	NS	0.10**	0.17**	0.09**	0.06**	0.10**	NS	NS	NS	NS	NS	NS	0.49**
QOL Psychological fn	NS	NS	NS	NS	NS	NS	(-)0.30**	NS	NS	0.54**	0.31**	0.26**	NS	NS	NS	NS	NS	NS	0.08**	NS	NS	0.30**	0.06**	0.05*	NS	NS	0.45**
QOL Social functioni	NS	NS	NS	NS	NS	NS	(-)0.38**	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS	0.12**
QOL Environment	NS	NS	(-)0.25**	0.25**	0.32*	(-)0.31*	NS	NS	NS	NS	NS	NS	0.31**	0.22**	NS	0.06**	0.05*	0.07**	0.09**	NS	NS	NS	NS	NS	NS	(-)0.01**	0.48**

Note: \*\*p<0.01; \*p<0.05

Table 7 indicates a summary of the regression analysis for quality of life and its dimensions of physical functioning, psychological functioning, social functioning, and environment. The total quality of life was predicted by the planning, behavioural disengagement, and humor dimensions of brief cope, and the consequences, and illness concern dimensions of the brief illness perception. The physical functioning dimension of quality of life was predicted by the humor and venting dimensions of brief cope, and the identity, treatment control, and coherence dimensions of the brief illness perception. The psychological functioning dimension of quality of life was predicted by the acceptance, and self distraction dimensions of brief cope, and the treatment control, and personal control dimensions of the brief illness perception. The social functioning dimension of quality of life was predicted by the coherence dimension of brief illness perception. The environment dimension of quality of life was predicted by the behavioural disengagement, humor, and active coping dimensions of brief cope, and illness concern, and identity dimensions of brief illness perception.

**Table 8** -Stepwise regression analyses showing various models predicting total quality of life in adolescent girls with beta thalassemia (N=44)

Predictor	R	ΔR <sup>2</sup>	β
	<u>Criterion: Total Quality of Life</u>		
Model 1	0.498	0.24**	
1. BC Planning			0.49**
Model 2	0.581	0.08**	
1. BC Planning			0.45**
2. BIP Consequences			(-)0.30**
Model 3	0.667	0.10**	
1. BC Planning			0.47**
2. BIP Consequences			(-)0.39**
3. BC Behavioral Disengagement			(-)0.34**
Model 4	0.713	0.06**	
1. BC Planning			0.36**
2. BIP Consequences			(-)0.47**
3. BC Behavioral Disengagement			(-)0.33**
4. BIP Illness Concern			0.28**
Model 5	0.762	0.07**	
1. BC Planning			0.33**
2. BIP Consequences			(-)0.38**
3. BC Behavioral Disengagement			(-)0.47**
4. BIP Illness Concern			0.33**
5. BC Humor			0.33**
Total R <sup>2</sup>			0.58**

Note: \*\*p<0.01; \*p<0.05, N= 44, β = Standardized Beta Coefficient, R = co-efficient of correlation, Δ R2 = change in R squared

A stepwise regression was performed to evaluate whether planning, consequences, behavioural disengagement, illness concern, and humor are able to predict total quality of life in adolescent girls with beta thalassemia. The contribution of the dimension of planning in predicting the total quality of life was 24%. Consequences dimension of brief illness perception contributed 8% to total quality of life. The behavioural disengagement dimension of brief cope contributed 10% in predicting the total quality of life. The illness concern dimension of brief illness perception and the humor dimension of the brief cope contributed 6% and 7% respectively in predicting total quality of life. The positive β value of brief cope planning showed a positive correlation with total quality of life (β= 0.49). The negative β value of brief illness perception consequences showed a negative correlation with total quality of life (β= -0.30). The negative β value of brief cope behavioural disengagement showed a negative correlation with total quality of life (β= -0.34). The positive β value of brief illness perception illness concern showed a positive correlation with total quality of life (β= 0.28). The positive β value of brief cope humor showed a positive correlation with total quality of life (β= 0.33).

**Table 9** -Stepwise regression analyses showing various models predicting physical functioning dimension of quality of life in adolescent girls with beta thalassemia (N=44)

Predictor	R	ΔR <sup>2</sup>	β
	<u>Criterion: QOL Physical functioning</u>		
Model 1	0.413	0.17**	
1. BIP Identity			(-)0.41**
Model 2	0.511	0.09**	
1. BIP Identity			(-)0.45**
2. BIP Treatment Control			(-)0.30**
Model 3	0.605	0.10**	
1. BIP Identity			(-)0.36**
2. BIP Treatment Control			(-)0.41**
3. BC Humor			0.35**
Model 4	0.668	0.08**	
1. BIP Identity			(-)0.31**
2. BIP Treatment Control			(-)0.63**
3. BC Humor			0.35**
4. BIP Coherence			0.36**
Model 5	0.743	0.10**	
1. BIP Identity			(-)0.29**
2. BIP Treatment Control			(-)0.72**
3. BC Humor			0.55**
4. BIP Coherence			0.42**
5. BC Venting			(-)0.37**
Total R <sup>2</sup>			0.55**

Note: \*\*p<0.01; \*p<0.05, N= 44, β = Standardized Beta Coefficient, R = co-efficient of correlation, Δ R2 = change in R squared

A stepwise regression was performed to evaluate whether identity, treatment control, humor, coherence, and venting are able to predict physical functioning dimension of quality of life in adolescent girls with beta thalassemia. The contribution of identity and the treatment control dimensions of brief illness perception in predicting physical functioning dimension of quality of life were 17% and 9% respectively. The dimension of humor of brief cope contributed 10% to physical functioning dimension of quality of life. The coherence dimension of the brief illness perception and the venting dimension of brief cope contributed 8% and 10% respectively to the physical functioning dimension of quality of life. The negative  $\beta$  value of brief illness perception identity showed a negative correlation with the physical functioning dimension of quality of life ( $\beta = -0.41$ ). The negative  $\beta$  value of brief illness perception treatment control showed a negative correlation with the physical functioning dimension of quality of life ( $\beta = -0.30$ ). The positive  $\beta$  value of brief cope humor showed a positive correlation with the physical functioning dimension of quality of life ( $\beta = 0.35$ ). The positive  $\beta$  value of brief illness perception coherence showed a positive correlation with the physical functioning dimension of quality of life ( $\beta = 0.36$ ). The negative  $\beta$  value of brief cope venting showed a negative correlation with the physical functioning dimension of quality of life ( $\beta = -0.37$ ).

**Table 10** -Stepwise regression analyses showing various models predicting psychological functioning dimension of quality of life in adolescent girls with beta thalassemia (N=44)

Predictor	R	$\Delta R^2$	$\beta$
<u>Criterion: QOL</u>			
<u>Psychological functioning</u>			
Model 1	0.549	0.30**	
1. BC Acceptance			0.54**
Model 2	0.62	0.08**	
1. BC Acceptance			0.46**
2. BIP Treatment Control			(-)0.3*
Model 3	0.671	0.06**	
1. BC Acceptance			0.5*
2. BIP Treatment Control			(-)0.47**
3. BIP Personal Control			0.31**
Model 4	0.712	0.05*	
1. BC Acceptance			0.41**
2. BIP Treatment Control			(-)0.46**
3. BIP Personal Control			0.37**
4. BC Self Distraction			0.26**
Total R <sup>2</sup>			0.50**

Note: \*\* $p < 0.01$ ; \* $p < 0.05$ , N = 44,  $\beta$  = Standardized Beta Coefficient, R = co-efficient of correlation,  $\Delta R^2$  = change in R squared

A stepwise regression was performed to evaluate whether acceptance, treatment control, personal control, and self distraction are able to predict psychological functioning dimension of quality of life in adolescent girls with beta thalassemia. The contribution of acceptance dimension of brief cope in predicting the psychological dimension of quality of life was 30%. The treatment control and personal control dimensions of brief illness perception contributed 8% and 6% respectively to the psychological dimension of quality of life. The self distraction dimension of brief cope contributed 5% to the psychological functioning dimension of quality of life. The positive  $\beta$  value of brief cope acceptance showed a positive correlation with the psychological functioning dimension of quality of life ( $\beta = 0.54$ ). The negative  $\beta$  value of brief illness perception treatment control showed a negative correlation with psychological functioning dimension of quality of life ( $\beta = -0.3$ ). The positive  $\beta$  value of brief illness perception personal control showed a positive correlation with psychological functioning dimension of quality of life ( $\beta = 0.31$ ). The positive  $\beta$  value of brief cope self distraction showed a positive correlation with psychological functioning dimension of quality of life ( $\beta = 0.26$ ).

**Table 11** -Stepwise regression analyses showing various models predicting social functioning dimension of quality of life in adolescent girls with beta thalassemia (N=44)

Predictor	R	$\Delta R^2$	$\beta$
<u>Criterion: QOL</u>			
<u>Social Functioning</u>			
Model 1	0.387	0.14**	
1. BIP Coherence			(-)0.38**
Total R <sup>2</sup>			0.14**

Note: \*\* $p < 0.01$ ; \* $p < 0.05$ , N = 44,  $\beta$  = Standardized Beta Coefficient, R = co-efficient of correlation,  $\Delta R^2$  = change in R squared



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A stepwise regression was performed to evaluate whether coherence is able to predict social functioning dimension of quality of life in adolescent girls with beta thalassemia. The coherence dimension of the brief illness perception contributed 14% in predicting the social functioning dimension of quality of life. The negative  $\beta$  value of brief illness perception coherence showed a negative correlation with the social functioning dimension of quality of life ( $\beta = -0.38$ ).

**Table 12** -Stepwise regression analyses showing various models predicting environment dimension of quality of life in adolescent girls with beta thalassemia (N=44)

Predictor	R	$\Delta R^2$	$\beta$
Criterion: QOL Environment			
Model 1	0.479	0.22**	
1. BC Planning			0.47**
Model 2	0.567	0.09**	
1. BC Planning			0.53**
2. BIP Identity			(-)0.31**
Model 3	0.62	0.06**	
1. BC Planning			0.56**
2. BIP Identity			(-)0.35**
3. BC Behavioral Disengagement			(-)0.25**
Model 4	0.676	0.07**	
1. BC Planning			0.52**
2. BIP Identity			(-)0.27**
3. BC Behavioral Disengagement			(-)0.4**
4. BC Humor			0.32**
Model 5	0.715	0.05*	
1. BC Planning			0.43**
2. BIP Identity			(-)0.3**
3. BC Behavioral Disengagement			(-)0.41**
4. BC Humor			0.38**
5. BIP Illness Concern			0.25**
Model 6	0.749	0.05**	
1. BC Planning			0.19**
2. BIP Identity			(-)0.29**
3. BC Behavioral Disengagement			(-)0.39**
4. BC Humor			0.41**
5. BIP Illness Concern			0.30**
6. BC Active Coping			0.31**
Model 7	0.738	(-)0.01**	
1. BIP Identity			(-)0.27**
2. BC Behavioral Disengagement			(-)0.38**
3. BC Humor			0.45**
4. BIP Illness Concern			0.36**
5. BC Active Coping			0.44**
Total R <sup>2</sup>			0.54**

Note: \*\*p<0.01; \*p<0.05, N= 44,  $\beta$  = Standardized Beta Coefficient, R = co-efficient of correlation,  $\Delta R^2$  = change in R squared

A stepwise regression was performed to evaluate whether planning, identity, behavioural disengagement, humor, illness concern, and active coping are able to predict environment dimension of quality of life in adolescent girls with beta thalassemia. The planning dimension of brief cope contributed 22% to the environment dimension of quality of life. The identity dimension of the brief illness perception contributed 9% to the environment dimension of quality of life. Behavioural disengagement and humor dimensions of the brief cope contributed 6% and 7% respectively in predicting the environment dimension of quality of life. Illness concern dimension of brief illness contributed 5% to the environment dimension of quality of life. The contribution of active coping dimension of the brief cope in predicting the environment dimension of quality of life was 5%. The positive  $\beta$  value of brief cope planning showed a positive correlation with the environment dimension of quality of life ( $\beta = 0.47$ ). The negative  $\beta$  value of brief illness perception identity showed a negative correlation with the environment dimension of quality of life ( $\beta = -0.31$ ). The negative  $\beta$  value of brief cope behavioural disengagement showed a negative correlation with the environment dimension of quality of life

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life ( $\beta = -0.25$ ). The positive  $\beta$  value of brief cope humor showed a positive correlation with the environment dimension of quality of life ( $\beta = 0.32$ ). The positive  $\beta$  value of brief illness perception illness concern showed a positive correlation with the environment dimension of quality of life ( $\beta = 0.25$ ). The positive  $\beta$  value of brief cope active coping showed a positive correlation with the environment dimension of quality of life ( $\beta = 0.31$ ).

**Table 13-** Mean, Standard Deviation and the *t* value for adolescent boys and girls with beta thalassemia for Illness Perception, Coping, and Quality of Life (N=100)

Variable Studied	Boys (N=56)		Girls (N=44)		<i>t</i>
	Mean	S.D	Mean	S.D	
Brief Cope Self Distraction	6.26	1.25	6.27	1.57	-.01
Brief Cope Active Coping	5.25	1.58	5.50	1.84	-.72
Brief Cope Denial	2.92	1.39	3.20	1.51	-.94
Brief Cope Substance Use	2.00	0.00	2.02	.15	-1.13
Brief Cope Use of Emotional Support	6.69	1.46	6.40	1.72	.89
Brief Cope Use of Instrumental Support	6.07	1.59	6.25	1.80	-.52
Brief Cope Behavioral Disengagement	3.25	1.55	3.22	1.50	.07
Brief Cope Venting	2.89	.98	3.31	1.28	-1.87
Brief Cope Positive Reframing	5.83	1.61	5.52	1.62	.97
Brief Cope Planning	4.92	1.55	5.22	1.72	-.90
Brief Cope Humor	2.71	1.49	2.70	1.33	.03
Brief Cope Acceptance	6.41	1.60	6.22	1.66	.55

Note: \*\* $p < 0.01$ ; \* $p < 0.05$   
df= 98

**Table 13 Continued**

Variable Studied	Boys (N=56)		Girls (N=44)		<i>t</i>
	Mean	S.D	Mean	S.D	
Brief Cope Religion	6.62	1.77	6.59	1.72	.09
Brief Cope Self Blame	2.48	1.17	2.84	1.32	-1.43
Total Brief Illness Perception	42.92	8.01	40.75	9.35	1.25
Brief Illness Perception- Consequence	6.33	2.59	5.88	2.65	.85
Brief Illness Perception- Timeline	7.78	2.87	7.20	3.09	.96
Brief Illness Perception- Personal Control	3.17	2.62	2.59	2.03	1.22
Brief Illness Perception Treatment Control	1.46	1.99	1.52	2.07	-1.14
Brief Illness Perception- Identity	7.19	2.26	7.40	2.47	-.44
Brief Illness Perception- Illness Concern	7.57	2.49	7.65	2.55	-.17
Brief Illness Perception- Coherence	2.80	2.48	1.97	2.21	1.72
Brief Illness Perception Emotional Representation	6.58	2.32	6.50	2.71	.17
Total Quality of Life	92.73	9.71	92.22	9.76	.25
Quality of Life – Physical Functioning	24.71	2.41	24.43	2.63	.55
Quality of Life Psychological Functioning	20.46	2.47	21.00	3.45	-.90
Quality of Life – Social Functioning	11.51	1.00	11.43	1.31	.37
Quality of Life – Environment	28.12	4.92	28.63	4.52	-.53

Note: \*\* $p < 0.01$ ; \* $p < 0.05$   
df= 98

Table 13 indicated that there were no significant differences between boys and girls with respect to the self-distraction, active coping, denial, substance use, use of emotional support, use of instrumental support, behavioural disengagement, venting, positive reframing, planning, humour, acceptance, religion, and self-blame dimensions of brief cope; total brief illness perception and its dimensions of consequence, timeline, personal control, treatment control, identity, illness concern, coherence, and emotional representation; total quality of life and its dimensions of physical functioning, psychological functioning, social functioning, and environment ( $p > 0.05$ ).

## V. DISCUSSION

The objective of the current research endeavour was to examine whether illness perception and coping predict quality of life in adolescent boys and girls with beta thalassemia. Stepwise regression was done for this purpose. The predictor variables were illness perception and its 8 dimensions (viz., consequences, timeline, personal control, treatment control, identity, coherence, emotional representation, and illness concern); and coping, measured in terms of its 14 dimensions (viz., self-distraction, active coping, denial, substance use, use of emotional support, use of instrumental support, behavioral disengagement, venting, positive reframing, planning, humor, acceptance, religion, and self blame); and the criterion variables were quality of life and its 4 dimensions (viz., physical functioning, psychological functioning, social functioning, and environment). The results of the study indicated that the dimensions of acceptance, use of emotional support, the total brief illness perception, identity, humor and self distraction predict quality of life and its 4 dimensions of physical functioning, psychological functioning, social functioning, and environment in adolescent boys with beta thalassemia. Consistent with previous research in other chronic illnesses, greater personal control and fewer consequences were associated with better physical quality of life (Alsén, Brink, Persson, Brändström, & Karlson, 2010; Scharloo et al., 2007; Vaughan, Morrison, & Miller, 2003).

In the present study, stepwise regression was also done in order to find out whether illness perception and coping predict quality of life in adolescent boys and girls with beta thalassemia. The predictor variables were illness perception and its 8 dimensions (viz., consequences, timeline, personal control, treatment control, identity, coherence, emotional representation, and illness concern); and coping, measured in terms of its 14 dimensions (viz., self-distraction, active coping, denial, substance use, use of emotional support, use of instrumental support, behavioral disengagement, venting, positive reframing, planning, humor, acceptance, religion, and self blame); and the criterion variables were quality of life and its 4 dimensions (viz., physical functioning, psychological functioning, social functioning, and environment). The results indicated that the dimensions of planning, consequence, behavioral disengagement, illness concern, humor, identity, treatment control, coherence, venting, acceptance, personal control, self distraction, and active coping predict quality of life and its 4 dimensions of physical functioning, psychological functioning, social functioning, and environment in adolescent girls with beta thalassemia. These findings are not in accordance with the findings of the previous studies which indicated that various disease groups have focused primarily on cognitive representation of illness (Broadbent, 2010).

Furthermore, the present study indicated no significant gender differences with respect to the self distraction, active coping, denial, substance use, use of emotional support, use of instrumental support, behavioral disengagement, venting, positive reframing, planning, humor, acceptance, religion, and self-blame dimensions of brief cope. In other words, there was no difference between boys and girls with beta thalassemia in terms of the coping strategies used by them to cope with their illness. The results are consistent with research showing that there are more gender similarities than differences in the use of coping (Hoar, Crocker, Holt & Tamminen, 2010). Researchers Hoar et al. (2006) suggested that the absence of gender differences may also be due to the age-related differences, since adolescents are likely to have a narrower coping repertoire.

The results of this study also indicated no significant differences between boys and girls with beta thalassemia in terms of total brief illness perception and its dimensions of consequence, timeline, personal control, treatment control, identity, illness concern, coherence, and emotional representation. These findings are not in accordance with previous researches done on gender differences in illness perceptions. The contradictory findings of the present study can be explained in the light of a study conducted by Chen, Tsai and Chou (2011) on illness perceptions and adherence to therapeutic regimens among patients with hypertension. The findings of the study suggested that illness perceptions may directly affect patient's adherence to prescribed medications or indirectly affect patient adherence via control of the disease and cause. The better the adherence, the better is the perception of the illness and vice versa in boys and girls with chronic illness. The patients in the present study adhered to the same kind of treatment and in a similar manner, and thus show no gender differences in their illness perceptions. Furthermore, illness causal attribution had been a major research focus in patients with a chronic illness (Khoury et al., 2012). Finally, beliefs about an illness's etiology may also affect patient emotional response (Petrie & Weinman, 2006). The patients in the present study, both boys and girls, received the same kind of treatment and took similar actions in order to control the symptoms. Hence, they showed no gender differences in their illness perceptions.

The results further reported no significant differences between boys and girls with beta thalassemia with respect to total quality of life and its dimensions of physical functioning, psychological functioning, social functioning, and environment. This finding is contradictory to the findings of a study conducted on the quality of life of patients with heart failure by Riedinger et al. (2001). The results of the study concluded that women had significantly worse general life satisfaction, physical function, and social and general health scores than men. Dunkel and Bennett (1990) propose that social support can have positive effects on well-being. Further, the matching hypothesis assumes that social support is better able to buffer the ill-effects of stress when the type

of support matches the needs elicited by the stress (Cohen & Wills, 1985). Finally, the absence of gender differences in the quality of life was also influenced by the patient's socio economic status. A study was conducted by Pawlinska, Wronka and Marchewka (2013) on the effect of socio-economic status on quality of life in people affected with respiratory allergy. The findings reported that the differences in quality of life were statistically significant with the socioeconomic variables. In the present study, both boys and girls with beta thalassemia belonged to the lower socioeconomic status (per monthly income was less than 20,000), and hence reported no gender differences in their quality of life.

### **Implications**

The present study has potential implications for future research. Future research may be conducted on the caregivers, especially the parents of thalassemic patients. Parents of thalassemic children experience higher degrees of distressfulness when compared with parents of normal children (Huijts et al., 2005). Moreover, teaching coping strategies to increase the behaviors associated with problem-focused coping and decrease the behaviors associated with emotion-focused coping should be a part of the treatment program. The use of problem-focused coping strategies can lead to effective confrontation of the adolescents with the complications of the illness thereby having a positive impact on their quality of life. Genetic counseling and prenatal screening could be emphasized that would raise the awareness about the disease and work towards decreasing the prevalence of beta thalassemia.

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