

# Hope and health related life quality among thalassemic patients

## Abstract

**Background:** This research examined the hope and health related life quality among thalassemic patients, mainly focusing on thalassemic patients with either on initial or advance stage. The study was aimed at exploring the hop in relation to the health related quality of life among thalassemic patients.

**Method:** A cross-sectional study design was utilized. A sample of diagnosed male and female thalassemic patients, at initial or advanced stage, (N=60). The tools used were: the Urdu version of the Herth hope index and the sf-36 of quality of life scale.

**Result:** The results exhibited strong relationship between the hope and quality of life. Further result study also proved, significant gender and severity and condition of disease base differences, showing male Thalassemic patients with higher level of hoper in comparison to female thalassemic patients. Additionally, the thalassemic patients at initial stage of the disease of both genders had a higher level of hope than the patients at advanced stage of disease. On the other hand, female thalassemic patients experience higher quality of life than male patients.

**Conclusion:** The results emphasize the preponderant importance of psychological measures to evaluate and provide thalassemic patients with a psychological support and help to improve the level of hope and health related quality of life among thalassemic patients.

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## Introduction

Thalassemia is life-long disabling heritable disorder; need repetitive blood transfusion procedure. Thalassemia is among the most common genetic blood disorders worldwide.<sup>1</sup> In Pakistan, 50,000 to 100,000 patients are suffering from thalassemia and every year 5,000 babies are born with thalassemia. In Pakistan, 5% of the total population suffers from thalassemia. It was found noteworthy harmful impact of thalassemia in areas of physical and mental health.<sup>2</sup> They confront with number of side effects predominantly exceeding level iron in body vital organs and heart, liver etc.<sup>3</sup> Many studies have investigated the link of between hope and quality of life. Hope has been linked to wellness and illness experiences and recovery.<sup>4,5</sup> It is thought to be necessary for survival of people with chronic diseases. Studies suggest that higher levels of hope are related to better outcomes in academics, athletic competitions and health.<sup>6</sup> Hope has been studied by various disciplines such as social sciences, psychiatry, theology and nursing. Hope is a central concept of positive psychology.<sup>7,8</sup>

Hope has been identified as a significant emotional and intellectual attribute of individuals with lifelong diseases and it has been described as essential to life.<sup>4</sup> Hope has many dimensions that change in different situations and hope has been identified as a positive attribute in chronic illness.<sup>9</sup> Hope allows individuals to have positive expectations of their present and future circumstances.<sup>10</sup> Attributes of hope include realistic understanding of circumstances, ability to consider alternatives and ability to set goals.<sup>11,12</sup>

One literature review explored hope as an emerging concept for nursing.<sup>5</sup> A strong link between hope and health was noted. Findings suggest that hope is based upon personal beliefs and adaptations to changes in family, health and environment that leads individuals to form a new and positive outlook or expectation of the future. Hope is linked to attaining goals and positive health outcomes. Setting

realistic goals require cognitive process and energy focused upon attaining goals. Hopelessness, despair and loss of control cause vulnerable people to be at higher risk for poor health outcomes. Nursing interventions have a direct impact on patient outcomes and the literature suggests that nurses should learn about ways to foster hope when planning care and setting goals with their patients.

A considerable number of journal articles and research studies have examined the role of hope with mental illness or with terminal illness and critical illness such as cancer, HIV and trauma.<sup>13,14</sup> Fewer articles study hope with aging and chronic illness such as chronic pulmonary disease and post-stroke.<sup>15,16</sup> Research revealed that levels of hope were positively related to physical health, mental health, psychosocial support and control of life. Those with impaired health maintained hope when relying upon other variables such as solid psychosocial support or ability to control their lives and futures. Thalassemia as a devastating disease may adversely influence patient's hope regarding health. Traumatic events such as pain, disease metastasis, recurrence, and severity may have negative effect on patients' hope levels.<sup>17,18</sup> It also results in to lowering patients' quality of life.<sup>19</sup> Hope in with thalassemia patients may be a predictor of good health.<sup>20</sup> It was found that that people with less hopeful are more susceptible to depressive symptomology however people with higher level of hope can easily accommodate in any condition or experience lower level of anxiety and had positive treatment outcome.

The Quality of Life of thalassemia patients get negatively influenced by psychological effect of diagnosis and treatment, long-lasting physical condition, repeated hospital visits for transfusion, and fears and reservations about the future.<sup>21,22</sup> Health related quality of life mainly stresses the effects of ailment and treatment on the patient's psychological health.<sup>23</sup> People with more hopeful regarding the life long illness like cancer, cardiac diseases and thalassemia generate more healthy coping strategies.<sup>24</sup> Also, they are more

expected to be practicing more the precautionary measures, such as maintaining their physical state and, additionally, and keep frequent follow up visit to doctors and show more complaint behavior towards doctor’s suggestions and advice. Hope provokes an individual to set new goal line when the previous ones are no longer possible because of the disease, and also to come up with substitute ways for achieving the aims, when the illness hold back them from reaching their goals.

This research topic concerns hope and health related quality of life among thalassemic patients. The topic was taken with respect to the following aims of the study: first of all to understand the relationship between hope and the health related quality of life for thalassemic patients; secondly, to fill the research gap in evidences and information about thalassemic patients interrelated to the health related hope and quality of life, specifically focusing on patients with thalassemia.

**Statement of the problem**

Thalassemia is a lifelong inheritable disorder, which involves both medically and psychologically treatment. Psychological factors and elements are proved to be very importance for the patient to improve the felt level of hope and health related quality of life. Presently, in the Pakistan there is a research gap regarding the effect of the psychological help and support in connection with Thalassemic patients. On the other hand, present study intends to explore the health related hope and quality of life for Thalassemic patients in Pakistan. Present study results will offer direction and guidance for psychologist and physicians with facts and findings about positive effect of psychological factors in order to provide suitable psychological strategy ranging from the psychological assessment to therapeutic intervention for thalassemic patients. The hypotheses of the study are;

1. There are significant associations between Thalassemic patient’s healths related hope and quality of life.
2. Sociodemographic factors will show significant difference on health related hope and quality of life.
3. Stage of disease of Thalassemia will show significant difference with reference to health related hope and quality of life.

**Methodology**

**Design and setting**

Present study based on descriptive correlation (cross-sectional) design investigated the correlation between hope and health related quality of life, as well as explored the health related quality of life as dependent variables, with hope thalassemia category as independent variables. Convenience sampling technique was used to select the sample of Thalassemic patients. All the patients were from Blood disease center Mansehra.

**Participants**

All the study subjects were belonging to different regions of KPK Pakistan. Study sample comprised of male and female diagnosed Thalassemic patients with the age range from 18 and above, and had ability to understand and comprehend Urdu questionnaires. Some patients who were approached and asked to take part, refused to participate in the study.

**Sample Size**

The latest issued census for the Thalassemic patients was in 2016 at Blood Disease Centre is 552. In the chase of the elected purposes

and quantitative study was chosen, defining the study population as thalassemia patients of District Mansehra. For present study using purposive convenient sampling technique sample of 60 diagnosed thalassemia patients (30 male and 30 female) were taken from hospitals of District Mansehra. For the present study only those participants were included who have the diagnosis of thalassemia with either at initial and advance stages of their disease.

**Research design**

In the present study purposive sampling technique was used for sample selection from diagnosed thalassemic patient’s population of Mansehra. Sample size was (N = 60) with further division which refers to severity of disease (initial stage=30, advance stage=30). The present sample was divided into two categories male and female.

**Materials**

**The herth hope index**

The HHI is a 12 item measure that probes inner thoughts and feelings about outlook on life, goals and fears. Scores range from 12 to 48, with 12 as the lowest score and 48 as the highest. Response category ranges from strongly disagree to strongly agree. The higher scores represent the greater level of hope. The HHI was determined as a valid instrument to measure hope.<sup>25</sup> The HHI was tested for reliability via test retest and internal consistency and findings revealed Cronbach’s alpha scores of .91 and .97, respectively.<sup>25</sup> Evaluation of questions and subscales revealed stability over time. The internal consistency of the HHI was scored as Cronbach’s alpha score of .94, which is considered good validity.

**SF-36 questionnaire**

The SF-36 consists of 36 questions and requires 10 minutes to administer. The Sf-36 includes a multi-item scale with 8 subscales: physical functioning, role limitations due to physical problems, bodily pain, general health perceptions, vitality, social functioning, role-limitations due to emotional problems, and mental health. A physical summary and a mental summary are included in the test scoring. A Cronbach alpha rating ranging from 0.67 to .94 was calculated for the eight subscales.

**Procedure**

With the permission from hospital diagnosed thalassemic patients were selected. The subjects were approached individually after obtaining informed consent questionnaires were handed to them. Patients were requested to respond to each item of scale. They were assured that information will be kept confidential and will be only used for research. Demographic information was also gained. At the end all participants were thanked.

Results of Table 1 indicate significant positive correlation between Hope and QOL which shows that Hope and QOL are positively correlated.

**Table 1** Correlation Coefficient between hope and quality of life questionnaire (N=60)

Scale	Hope	QOL	M	SD
1	-	.633**	49.32	12.84
2	-	-	32.65	9.63

\*\*p<.01, \*p<.05

Table 2 indicates significant severity of disease base differences on hope whereas on QOL the difference is non-significant which shows that advance stage of the disease have low level of Hope as compared to patients at the initial stage of the disease.

Table 3 shows significant gender base differences on Hope and QOL which indicates that level of Hope and Quality of life is high among male patients as compared to female thalassemic patients.

**Table 2** Mean, Standard Deviation, and t-values severity of disease of hope and quality of life questionnaire (QOL) N=60

	Initial (n=30)		Advance (n=30)		t(58)	p	95 % C.I		Cohen's d
	M	SD	M	SD			UL	LL	
Hope	45.93	13.9	52.7	10.85	2.09	0.002	5.56	1.3	0.84
QOL	31.87	9.71	33.43	9.65	0.626	0.015	10.77	1.22	0.65

Note. QOL = Quality of life

**Table 3** Mean, Standard Deviation, and t-values of scores of male and female patients on hope scale and Quality of life Scale (QOL) N=60

	Male (n=30)		Female (n=30)		t(58)	p	95 % C.I		Cohen's d
	M	SD	M	SD			UL	LL	
Hope	53.7	9.74	44.93	14.74	2.79	0.002	5.56	1.3	0.84
QOL	35.8	8.77	29.5	9.56	2.65	0.015	10.77	1.22	0.65

## Discussion

Firstly the conducted assessment of relationship between hope and quality of life study result showed that significant positive relationship exist between hope and health related quality of life among Thalassemia patients. This is consistent with the hypothesis; there will be significant positive relationship between hope and health related quality of life. The data analyses regarding gender difference showed that there is significant gender difference of Thalassemic patients on HHI and SF-36, male patients with Thalassemia were more hopeful and better with reference too quality of life. The possible explanation of higher level of hope in male patients is that in context to Pakistani culture, male child always get extra care and treatment than female child. Contrary to present study findings, female patients are proved to be more hopeful than male patients with Thalassemia.<sup>26</sup> Present study also showed that female patients with thalassemia have more physical and emotional problems than male patients. Evidence from Asian culture also proved higher prevalence rate of mental and physical health related issues among females with thalassemia as they get less medical facilities and care at home due to sociocultural factors.<sup>27</sup> Another study reported consist findings that parents pay more responsiveness to problems of male as compared to female thalassemic patients as a result the health quality of life among male patients is high as compared to female thalassemic patient.<sup>28</sup> According to data analysis hope and quality of life are high in initial staged as compared to advance staged thalassemic patients. Present study result is line with previous researches.<sup>29</sup> It is found that there is moderate to negative significant relationship with basic hope and such elements of quality of life as physical and emotional health among thalassemic patients on initial stage of disease.<sup>30</sup> These correlation refers that quality of life and hope decrease in advance stage in thalassemic patients.

## Conclusion

The present study was intended to explore the relationship between hope and quality of life among thalassemia patients. It was also aimed to find out gender and severity of disease. The results demonstrated that there is significant positive correlation between

hope and quality of life. The results of the current study demonstrated significant gender difference on HHI and SF-36 questionnaire. Mean scores indicates that male patients have high scores on HHI and SF-36. The results also showed significant difference on initial stage and advance stage. Result indicates level of hope and quality of life was comparatively high among thalamic patients diagnosed with initial stage of the disease as compared to patients at advanced stage of the disorder.

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## Conflicts of interest

The author declares that there is no conflict of interest.

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