

Impact of Death Anxiety and Psychological Distress on the Quality of Life of Thalassemia PatientsAlizay Siddique¹, Maham Imtiaz^{2*}, Iqra Ayaz¹**Abstract**

The purpose of this study was to explore the relationship between death Anxiety, psychological distress and quality of life among thalassemic patients. The quantitative research design was used, utilizing non probability purposive sampling to draw sample size of ($N=103$) adult thalassemic patients of aged 18 to 40 years. Consent form and demographic sheet was provided to each participant. Urdu versions of Death Anxiety Scale, Depression, Anxiety, Stress Scale (DASS-21), and EUROHIS-QOL-8 items Scale were administered to each participant. Data was analyzed by using regression analysis, Pearson correlation and independent t test. The regression analysis shows that death anxiety negatively impacts the quality of life of thalassemia patients ($\beta = -.62, p < .001$). The correlation analysis finds out that psychological distress is negatively correlated ($r = -.58^{**}$) with the quality of life. Further correlation analysis shows that psychological distress has stronger positive association ($r = .88^{**}$) with the death anxiety. The independent t test showed statistically significant gender difference in the psychological distress. The findings of this study will help nurses, health care professionals and thalassemic centers to improve the thalassemic patient's quality of life by applying interventions and appropriate therapies.

Keywords: Death Anxiety, Psychological Distress, Quality of Life, Thalassemia Patients

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Introduction**Thalassemia**

Thalassemia is an inherited (i.e., passed from parents to children through genes) blood disorder caused when the body doesn't make enough of a protein called hemoglobin, an important part of red blood cells (World Health Organization Quality of Life Assessment, 1995). It is characterized by diminished or absent production of one or

more globin chains that constitute hemoglobin. This condition results in chronic anemia, which may necessitate ongoing blood transfusions and iron chelation therapy. This condition can affect growth, development and quality of life, especially when left untreated or poorly managed (Motiani et al., 2024). This condition is categorized into α and β thalassemia. β - thalassemia is also known as Cooley's and Mediterranean anemia, usually detected in seriously ill patients and categorized as heterozygous and homozygous β thalassemia major.

Historically about 1.5% of the global population has been affected from β thalassemia (Colah et al., 2010). β thalassemia is about 5.2% worldwide according to WHO (Sari et al., 2022). Patients with thalassemia major so they require regular blood transfusions, medications, iron chelation therapy that affect the life of person (Nabi et al., 2022).

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However due to the progress of medical science and evolution in treatment helps thalassemia patients to live more than 50 years (Vitrano et al., 2017).

Thalassemia in the Pakistani Context

Asia has about 79% of thalassemic births. In Pakistan the percentage of thalassemia is about 5-8 % and there are 5000 children have the identification of thalassemia in Pakistan per annum (Ansari et al., 2012). Pakistan lies on the top of the list in which thalassemia has more prevalence unlike the other countries because they have no technological advancement, genetic counseling, premarital and prenatal screening (Zaheer et al., 2020). Annually about 7.8 billion is required annually for 60,000 enrolled thalassemic patients with much of cost covered by families and NGOs. The major load is on NGOs because the government does not provide enough support according to Journal of Pakistan Medical association.

Death Anxiety

Death anxiety is defined as the severe fear of death and dying of someone's own mortality. It is mostly common in chronically ill patients such as thalassemia. (Aziz et al., 2022). Patients with thalassemia major often experience heightened levels of anxiety due to frequent hospital visits, the need for strict adherence to treatment regimens, and the uncertainty regarding their life expectancy. Additionally, complications such as heart failure, liver disease, and infections contribute to their distress, making death anxiety a significant concern in this population (Waite-Jones & Rodriguez, 2022). Pakistan, a country deeply rooted in religious and cultural traditions, death is often viewed through a spiritual lens. However, despite religious beliefs providing comfort to many, the fear of death remains a significant psychological concern (Eyetsmitan, 2021). Thalassemia patients have a death anxiety that is of special concern as it has significant impact on their mental health, treatment compliance, quality of life and overall

wellbeing (Jabeen et al., 2024). There are no specific data on death anxiety in Pakistani thalassemia patients but evidence suggests that chronic illness patients have higher levels of thanatophobia than the general population. These patients tend to experience heightened death anxiety because of factors, such as frequent hospitalizations, medical complications, financial troubles, and doubt about the future (Eren et al., 2023). Patients suggested that who received CBT have reduced fear of death and better emotional capability so they are able to participate in social and physical activities (Mostafa et al., 2024).

Psychological Distress

Psychological Distress is a state characterized by unpleasant feelings and emotions (Psychological experience) that negatively affects a person's mental health and well-being. It involves mental disorders like psychological distress and PTSD. Children enduring chronic illnesses exhibit diminished overall health status and life satisfaction (Alkhaqani, 2022)

Young individuals afflicted with thalassemia experience reduced general health and report lower levels of life satisfaction (Ansari et al., 2024). A representative analysis of children diagnosed with thalassemia in Iran indicated that their general and emotional well-being was significantly compromised (Etemad et al., 2021) A survey conducted in Pakistan revealed that children afflicted with thalassemia experience exhibited symptoms of Psychological distress (Bibi et al., 2021). The chronic nature of thalassemia, which expect lifelong regular blood transfusion and third attention, is associated with challenges that give to hopelessness, Psychological distress, and mood trouble in affected patient (Aqeel et al., 2022; Shuja et al., 2021; Tarim & Öz, 2022).

Quality of Life (QoL)

An individual's perception of their position in life in the context of their culture and value systems, and in relation to their goals,

expectations and concerns. Thalassemia is a chronic disease so the patients suffer from this has an impact on their mental health due to unavailability of resources, treatment costs, regular blood transfusions, financial burden, personalized and social hurdles, treatment issues, community aid, body dysmorphic disorder, reduced self-esteem. The result of disease can badly impact the mental health such as noncompliance to treatment thus lead to poor QoL (Rikos et al., 2021). For thalassemia patients, QoL is significantly affected due to the chronic nature of the disease, lifelong medical dependency, frequent hospital visits, complications from iron overload, and psychosocial challenges. The impact of thalassemia on QoL varies globally, depending on healthcare accessibility, economic status, and social support systems (Taher et al., 2021). Women have low quality of life than men (Seyedifar et al., 2016). Females who experience more emotional damage due to lack of support are at higher risk of having low QoL than males (Afifi et al., 2022). The difference between lifestyles of both male and females may be due to societal pressure on males. Thalassemia patients have disturbed QoL and mental health so they require complete thalassemic supervision. Monitoring and precaution of psychological distress were suggested for thalassemic sufferer (Suryawan et al., 2021) Ahmadi et al. (2020) reported that 43% of thalassemia patients repetitive thoughts of death and 27.3% had experience suicidal ideation. Thalassemia Patients face psychological challenges due to the chronic burden of their disease and experience physical and emotional strain. Thalassemia, chronic disease that has psychological effects which leads to depression and suicidal ideation (Ghanizadeh et al., 2006). Thalassemia Patients experience death anxiety which leads to negative psychological outcomes so they have low coping ability and high level of distress.

(Ahmadi et al., 2020). A study stated that 55% of the Thalassemia patients have severe Depressive symptoms which leads to disturbed quality of life (Sarhan et al., 2022). A study conducted in Multan, Pakistan find out that in 80% population suffered from psychosocial maladjustment (Ishfaq et al., 2018). In Indonesia, a study examining adolescents diagnosed with thalassemia major revealed that 19.7% of this population experienced severe anxiety. The determinants exacerbating anxiety levels included negative body image, diminished self-esteem, and insufficient coping mechanisms. Adolescents possessing a detrimental self-image were found to be 11.6 times more predisposed to experiencing severe anxiety, thereby underscoring the pivotal importance of psychological interventions specifically designed for this demographic (Mediani & Fuadah, 2025). As Psychological distress is positively correlated with death anxiety and both are negatively correlated with quality of life.

The adults suffering from thalassemia may undergo more psychological distress that effect their QoL is an area which is under researched. Most of the studies on thalassemia mainly focus on the children and adolescents, but the adults with thalassemia often burdened with social stigma, ongoing treatment, they experience restrictions which make their career progress difficult. The study aims to fill out the gap by investigating the impact of death anxiety and psychological distress on the quality of life of adult thalassemia patients. The study will also fill the gap that these three variables have not been find out together in a study in Pakistan. Every culture has its own coping strategies, beliefs of mortality and alignments. The gap of this study is that there are different cultural values and traditions that affect the death anxiety and psychological distress and their effects on quality of life in thalassemia patients.

Objectives

- To assess the psychological distress among males and females.
- To assess the level of death anxiety in thalassemia patients.
- To evaluate the impact of death anxiety and psychological distress on the quality of life of thalassemia patients.

Hypotheses

- Females will score significantly higher at DASS -21 than males.
- Higher level of death anxiety predicts the lower quality of life among thalassemia patients.
- Psychological distress is negatively correlated with the quality of life in thalassemia patient.

Method**Research Design**

Cross sectional study with Quantitative research design was used to collect the data in order to find out the impact of death anxiety and psychological distress on the quality of life of thalassemic patients.

Sampling Strategy

In this research, non probability purposive sampling was used to draw the sample. Sample was ($N=103$) from the patients suffering from thalassemia within adults with the age limit of 18 to 40. Normality and homogeneity of variance were checked before applying t -test.

Table 1

Demographic Characteristics of the Sample of Thalassemia Patients (N= 103)

Demographic Characteristic		N	%	Demographic Characteristic		N	%
Age (years)	18-24	42	40.8	Education	Uneducated	20	19.4
	25-31	37	35.9		Primary-Matric	35	34.0
	32-40	24	23.3		Inter-Graduation	38	36.9
Gender	Male	58	56.3	Area of Residence	Above Graduation	10	9.7
	Female	45	43.7		Urban	43	41.7
Marital Status	Single	48	46.6	Monthly Income	Rural	60	58.3
	Married	41	39.8		No Earning	1	1
	Divorced	11	10.7		20k-30k	40	38.8
	Widow	3	2.9		30k-80k	53	51.5
Access to Healthcare	Good	28	27.2	Family Size	Above 80k	9	8.7
	Normal	31	30.1		0-3	26	25.2
	Low	44	42.7		4-6	47	45.6
Patient Caretaker	Parent/Sibling	61	59.2	Duration of Illness	7 or More	30	29.1
	Spouse	27	26.2		<5 years	31	30.1
	Any Other	15	14.6		6-10 years	35	34.0
				>10 years	37	35.9	

Inclusion Criteria

The population with Thalassemia major and age range of 18 to 40 of adult population was included because individual within this age group experience higher level of distress due to long term vulnerability to the disease and have social responsibilities so, have difficulties in managing disease. Participants included were diagnosed with thalassemia major, receiving regular blood transfusion and able to complete questionnaire independently or with assistance. Consent of patient's guardian and residence of Multan, Pakistan was necessary. In this research adults aged 18-40 were assessed.

Exclusion Criteria

The children were not the part of population. Patients with cognitive impairments were excluded because it reduces the quality of responses. The older adults were also not the part of population. Participants with severe psychiatric illness were excluded. Individuals with speech/hearing impairments were also excluded. The patients who deny to give consent were also excluded.

Instruments

Demographic Information Questionnaire (DIQ)

The DIQ contained questions related to age, education, gender, area of residence, marital status, monthly income, access to health care, family size, patient caretaker and duration of illness.

The Templer Death Anxiety Scale (DAS)

DAS was developed by Donald Templer in 1970, is one of the earliest and most widely used instruments for measuring death anxiety. This self-report scale includes 23 items, designed to assess an individual's level of anxiety related to thoughts of death and dying. Each respondent indicates on a 5-point scale, each point is scored from 0 to 4. Each item is scored as either 0 (no), 1 (a little), 2 (a fair amount), 3 (much), 4 (very much) resulting in a total score by the sum of the given answers, with higher scores indicating greater death anxiety. The scale has

demonstrated good reliability, with Templer reporting a Cronbach's Alpha of .76, suggesting acceptable internal consistency. It has good convergent validity. Urdu version of this scale was administered to the targeted population with Cronbach Alpha of .95.

Depression, Anxiety, Stress Scale (DASS-21)

Psychological distress was assessed using Urdu version of DASS-21. It consists of a set of three self-report subscales designed to measure the negative emotional status of depression, anxiety and stress. A respondent indicates on a 4-point scale, each point is scored from 0 to 3 (Lovibond & Lovibond, 1995). The DASS-21 Urdu has been found to have good internal consistency with Cronbach's α coefficients of .86 for Depression subscale, .88 for the Anxiety subscale and .87 for Stress subscale as well as excellent convergent validity. The DASS-21 Urdu was found to be a reliable and valid tool for measuring the mental health.

EUROHIS QoL 8-items Index

The QOL-8 instrument serves as a condensed variant of the WHOQOL-BREF, consisting of eight items derived from the Urdu version of the WHOQOL-BREF tool. Empirical evidence from various European investigations, including the European Health Interview Surveys (EUROHIS-QOL-8), has corroborated the satisfactory psychometric attributes of this abbreviated version. The items encapsulated within this scale correspond to each dimension of psychological, physical, social, and environmental domains, evaluated via a 5-point Likert scale that ranges from "not at all" to "completely." The scale has been assessed to possess reliability, validity, and cross-cultural applicability, not solely within European nations but also across numerous low-income countries. Each item of the WHOQoL-8 is appraised on a five-point continuum, with scores ranging from 1 (indicative of the lowest quality of life) to 5 (representing the highest quality of life); thus,

the cumulative score has a possible range extending from 5 to 40. Elevated scores are indicative of an enhanced quality of life (Schmidt et al., 2006).

Ethical Considerations

The participants who give their consent willingly were enrolled in the study. The clear purpose, pros and cons and process of study were explained before collecting data. The participants were given right to withdraw from the study whenever they want. Confidentiality was promised and participant identity was not revealed. Participants were assigned number codes instead of their names. The data collected from study was assessed only to the researcher and

supervisor. There was clear consideration for the psychological health of the participants. Ethical approval was taken from Recognized Institutional Review Board (Fatmid Foundation). The verbal explanation was given to the participants that were illiterate through structured interviews. The cultural perspectives were also taken under consideration.

Results

The hypotheses were tested by using SPSS 27.0. Regression analysis, Pearson correlation, and independent samples t test were used to test hypotheses. Frequency and percentages were calculated for demographic variables.

Table 2

Regression Analysis for Impact of Death Anxiety on the Quality of Life of Thalassemia Patients (N=103)

Variables	B	SE	t	p	95% CI	
					UL	LL
Constant	32.31***	1.14	28.35	.001	34.57	30.05
Death Anxiety	-.22***	.02	-8.03	.001	-.170	-.282

Table 2 confirmed that R^2 value of .38 showed that the predictors defined 38.4% variance in the dependent variable, and the

results showed that death anxiety was significant negative predictor of quality of life ($\beta = -.62, p < .001$).

Table 3

Correlation Coefficients for Psychological Distress and Quality of Life in Thalassemia Patients (N=103)

Variables	M	SD	1	2
Psychological Distress	58.81	25.46	--	
Quality of Life	24.14	6.64	-.58***	--

Results of the Table 3 revealed that negative correlation between psychological distress and quality of life ($r = -.58, p < .001$). This

indicates that higher level of quality of life is associated with lower level of psychological distress.

Table 4

Independent Samples t-test for Comparing Psychological Distress between Males and Females in Thalassemia Patients (N=103)

Variable	Males (n= 58)		Females (n= 45)		df	t	p	95%CI		Cohen's d
	M	SD	M	SD				LL	UL	
Psychological Distress	44.55	23.73	77.20	12.65	101	-8.34	.001	-40.40	-24.8	1.71

Results of the Table 4 revealed that level of psychological distress was slightly higher among females ($M = 77.20$, $SD = 12.65$) than males ($M = 44.55$, $SD = 23.73$). An independent t-test showed that the difference in psychological distress between males and female's participants was significant ($p <$

$.001$), and the size of this effect was large (Cohen's $d = 1.71$). The 95% confidence interval for the difference in means ranged from -40.40 to -24.8 , further indicating significant difference in psychological distress between the two groups.

Discussion

Research indicates that female thalassemia patients scored higher in the DASS-21 scale concerning the symptoms of psychological distress. In a systemic review of 23 studies reported that in 62% of the studies, females noted higher psychological distress and lower quality of life than males. Such disparity manifested across different cultures, pointing at the tendency seen in developed countries were female diabetic patients with thalassemia experience relatively worse mental health outcomes (Jamil et al., 2024). A more recent study by Khoury et al. (2013) that assessed the quality of life of these adult female major and intermedia β thalassemia patients found that they have higher scores of anxieties and depression as compared to their male counterparts. This is in concordance with other research done on the mental health soil wherein it has been determined that women are more vulnerable to moods and Anxiety (Khoury et al., 2013). The hypothesis results of this study also showed that females score significantly higher at DASS than males.

Another study was done with children with thalassemia and their families, the results showed that there was a negative relationship between psychological distress with self-rated general health and life satisfaction where the correlation coefficients were $r = -.34$ and $r = -.44$ respectively. The results obtained from this study imply that there is a direct poor relationship between psychological distress and perceived health and overall life satisfaction of a child (Ramzan & Ahmad, 2024). Namely, Azarkeivan et al. (2014) established that psychological distress had a detrimental effect on the patient's quality of life in thalassemia major or intermedia. Surprisingly, depression negatively affected both, the physical and psychological aspects of the individuals' lives while anxiety mainly targeted the mental sphere (Azarkeivan et al., 2014). There is a strong negative association between distress of psychological related issues and quality of life among the thalassemia patients. However, further and more significant improvements in the QoL of thalassemia patients can be attained if mental

health disorder are properly addressed with Interdisciplinary models of care (Anum & Dasti, 2016).

In a study, it is noted that HDF and associated longer RBC transfusion intervals yield considerable morbidities to TDBT patients, consolidate death anxiety that reduces QoL and dignity. The two important factors consist of the prolonged duration of the illness and the remembrance of death that negatively impact QoL. Saeed (2025) focused on the moderating role of death anxiety on level of depression and quality of life among cancer patient. Specifically, this research explored the impact of death anxiety and the fact that such despair can be reversed with better moods and increased quality of life according to psychological interventions for the symptom. The findings further suggest a strong negative relationship between death anxiety and quality of life in the thalassemia patients. However, differing from the above-mentioned dimensions, it has been found that mindfulness-based stress reduction, a type of psychological intervention for death anxiety, could enhance QoL. The results of our study align with the above results of the study. Death Anxiety is positively correlated with Psychological Distress. They contrast also support the need for consulting practitioners in mental health as part of the care of thalassemia patients. On quest study identified the association between depression and quality of life with mediating role of death anxiety among women cancer patients in Pakistan (Saeed, 2025).

In Pakistani cultural context, these findings should be considered according to social and cultural framework. As in other country, Pakistani thalassemia patients also undergo Physical, mental as well as social problems. Long term exposure to the disease, financial burden and dependency on the family lead to psychological distress. People with mental health problems are often stigmatized in Pakistan, so they become emotionally

burdened due to the cultural standards. There is low accessibility of mental health services and lack of social support in Pakistan. Consequently, there is a negative impact of Death Anxiety, Psychological Distress on the Quality of life.

Suggestions and Limitations

This study focuses on adults, future studies could compare different age groups (e.g., adolescents vs. Adults) to assess developmental differences in the experience of death anxiety and distress. Future research could assess the efficacy of specific psychological interventions (e.g., CBT, mindfulness, support groups) in reducing death anxiety and improving quality of life. Long-term follow-ups would help determine how death anxiety and psychological distress evolve over time and how they affect chronic illness management. So, the future studies could be longitudinal. This study is cross-sectional; it will limit the ability to establish causality between psychological variables and quality of life outcomes. The reliance on self-report instruments may lead to social desirability or recall bias, especially when dealing with sensitive topics like death and mental distress. Results may not generalize beyond the specific region, hospital, or demographic (e.g., adult Pakistani patients), restricting broader application. Because it has limited population so the results cannot be Generalized. Due to stigma around mental health in many cultures, participants might underreport symptoms of distress or anxiety. So, they might underreport the symptoms.

Implications

The study reflects the need for using psychological support into the daily routine for thalassemia patients. By discussing these factors can enhance treatment outcomes and quality of life. Support programs like counseling and patient groups help to reduce psychological distress. Promoting awareness about psychological distress of thalassemia patients can help alleviate stigma and

encouraging patients to seek mental health support.

Conclusion

The results showed complicated relationship between sex, surroundings, death anxiety and psychological distress among patients of thalassemia. Death Anxiety appears as a remarkable positive indicator of Psychological Distress and negative indicator of Quality of life, but rural population and female population showed higher level on those scales. These findings showed that people live in rural areas with lack of resources and female population suffering from Thalassemia face lot of psychological burdens. It is important to highlight the mental health concerns in the Thalassemia patients and culturally adapted interventions should be taken for gender sensitivity, and should pay attention to improve Quality of life and mental health by reducing Death Anxiety.

Ethics Statement

The study was conducted in accordance with the APA Ethical guidelines. Informed consent was obtained from all participants.

Contribution of Authors

Alizay Siddique: Conceptualization, Investigation, Methodology, Data Curation, Formal Analysis, Writing – Original Draft
Maham Intiaz: Methodology, Supervision, Writing - Reviewing & Editing
Iqra Ayaz: Methodology, Writing - Reviewing & Editing

Conflict of Interest

There is no conflict of interest declared by the authors.

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Data Availability Statement

The datasets of the current study are not available publicly due to ethical reasons but are available from the corresponding author [M.I.] upon the reasonable request.

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