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Mental Health-Related Issues and Quality of Life among Caregivers of Thalassemia Patients

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Abstract: Thalassemia is a lifelong heritable disorder that requires a repetitive blood transfusion procedure. Along with other challenges, caretakers of thalassemic patients must bear the psychosocial burden and stress. This research examined the quality of life of mental health-related issues among caregivers of thalassemic patients. Utilizing a cross-sectional study design, a sample of male and female caregivers /attendants of diagnosed thalassemic patients (N=180) were assessed using the Urdu version of the Quality of Life and The Depression Stress and Anxiety Scales. The results demonstrated a strong relationship between experienced mental health-related issues and quality of life. Further results study also showed substantial gender and family system base differences, showing that male caregivers of thalassemic patients had higher levels of quality of life and fewer mental health-related issues (depression, anxiety, and stress) level than female caregivers of thalassemic patients. Additionally, both gender caregivers of thalassemic patients belonging to the joint family system had a higher level of quality of life with mental health-related issues than the caregivers of thalassemic patients belonging to the nuclear family system.

Keywords: Mental Health, Thalassemia Patients, Blood Transfusion, Psychological Burden, Stress, Depression

Introduction

Thalassemia, as the most common form of inherited blood-related disease, needs lifelong management, such as blood transfusion, proper intake of medicines, iron supplements, and proper and healthy diet. Thalassemia is a pervasive genetically transmitted disorder of the blood. The body produces a peculiar form of hemoglobin, which requires regular blood transfusion is needed. This causes several psychosocial complications for patients, their caregivers, and other family members. Thalassemia is the most common form of genetic disease. In the modern world, it has been declared one of the most eminent lifelong diseases that significantly negatively impact an individual's overall psychosocial life. Thalassemia is a hereditary disorder that may result in several other psychosocial issues (Jamil et al., 2024).

In Pakistan, the occurrence rate of thalassemia is 5-7%, with 9.8 million, and each year, approximately 5000 children are born with thalassemia. Thalassemia major patients need frequent transfusions of blood and iron chelation therapy, which is a constant source of psychological problems for thalassemia major patients and their relatives (Shakoor et al., 2024). Up to 80% of caregivers of thalassemia patients are prone to have psychological issues. Even though patients with all types of blood disorders involve similar levels of stress, the caretakers of patients experiencing thalassemia major are distinctive because they regularly seek hospice treatment for the transfusion of blood (Askaryzadeh et al.,

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2023). Although in Pakistan numerous studies have been conducted on thalassemia, very little interest has been given to psychological issues confronted by caretakers of thalassemia patients. Overall, thalassemia affects many aspects of the caretaker's life, which often results in isolation, depression, and anxiety (Angane et al., 2022; Saqlain et al., 2022). In Pakistan, just like any other third-world country, Thalassemia patients are unable to get standardized treatment plans (Khaliq, 2022).

Caring for a family member who is ill usually involves the whole family struggle, which is mainly dictated by society and cultural norms. In Pakistani culture, it is generally suggested that women take up the obligation of being a family caregiver (Anum et al., 2016). Like any other lifelong disease, thalassemia not only burdens and inversely affects not only the thalassemia patient but also the whole family, especially female parents' mental health gets effected of the thalassemic patient is, directly and indirectly, gets affected. So, it is important to explore and analyze the psychological factors along with factors that significantly contribute to the healthy adjustment of these emic patients (Askaryzadeh et al., 2023). Studies have proved that mothers of children suffering from any lifelong disease are more vulnerable to developing psychological problems as these children's special needs, care, and treatment may result in a psychological burden on caregivers' disabilities have a significant part in support and care (Thiyagarajan et al., 2019).

This long-lasting disease is accompanied by many complications and problems both for the patients and their families. Children with Thalassemia must repeatedly visit the hospital for chelation therapy and blood transfusion (Liaquat et al., 2022; Sharma et al., 2016). Parents suffer from several psychosocial burdens because of expenditures, stress, and tension, and in extreme cases, may cause death anxiety. Along with the proper provision of medication, many other factors result in associated psychosocial problems that burden the caregivers to keep their daily activities healthy (Hood et al., 2024).

Researchers have also proved that caregivers of patients with lifelong medical conditions generally are more prone to developing psychological problems; specifically among mothers, the occurrence rate of depression is quite high. The highly reported causal factors of depression included regular hospital visits, low level of hope, disease-related other medical complications, and experienced financial problems. A study reported that 60.6% of caregivers of thalassemia patients were depressed (Poormansouri et al., 2016). Since thalassemia is a lifelong disease that directly and indirectly affects the quality of life of both the patient and caregivers. Studies have shown that a family is the focal and most vital source of social support for patients and relieves the psychological and social burden produced by a thalassemic medical condition (Rikos et al., 2021).

For healthy adjustment, thalassemia patients require social support from their families, doctors, and other members of society. Similarly, prevention against thalassemia-affected children and their families also needs medical, moral, social, and familial support (Yasmeen et al., 2024). Furthermore, operative management and social support also mainly depend upon general awareness about the ailment; therefore, the general population needs at least related basic awareness and information (Borgna-Pignatti, 2010). The present study aimed to investigate the Anxiety, Depression and quality of life among caregivers of thalassemia patients in Pakistan.

Statement of the Problem

Thalassemia is a lifetime ailment which requires both medical and psychological treatment. Currently, in Pakistan, there is a research gap about the possible effect of emotional help and care provided by caretakers to Thalassemic patients. On the other hand, the current study aims to explore the possible relationship between mental health-related issues and quality of life among caretakers and attendants of Thalassemic patients. The present study results will offer guidelines for psychologists and medical doctors with evidence about psychologically health-related factors among caretakers of thalassemic patients to offer appropriate psychological approaches extending from the assessment strategies to therapeutic techniques for caretakers of thalassemic patients. The hypotheses of the study are.

1. There is a significant relationship between mental health-related issues and quality of life among caregivers of thalassemia patients.
2. Sociodemographic factors base differences on mental health-related issues and quality of life among caregivers of thalassemia patients.

Methodology

Design and Setting

The present study, based on descriptive correlation (cross-sectional) design, examined the relationship between anxiety, depression, and quality of life among caretakers of thalassemic patients, as well as investigated the health-related quality of life as dependent variables, with depression, anxiety, and stress as independent variables. Using convenience sampling technique sample of caretakers and attendants of Thalassemic patients was selected from Blood Disease Center Mansehra.

Material and Methods

The current study was a quantitative cross-sectional study. The population of the present study included caretakers of thalassemia patients. Keeping the bound of the error to be 2.5%. A confidence level of 95% and a sample size of 180 were calculated. One eighty caretakers of thalassemic patients of both genders (male = 96 and female 84) were further divided into subcategories of the joint family system (JFS, n = 102) and nuclear family system (NFS, n = 78), respectively.

Potential subjects of the study were the male and female caretakers of thalassemic patients. Research subjects diagnosed with any serious mental disorder and who were not willing to participate were disqualified from the study.

The researcher personally contacted the potential subjects in a face-to-face manner. Along with briefing about the objectives of the study, they were assured of the confidentiality of the data and that at any phase of the study, they could leave as per their wish. After obtaining the informed consent, two Urdu version questionnaires naming quality of life and depression, anxiety, and stress scales were distributed to subjects.

The world-health-organization quality of life-BREF.– Self Report Twenty-six items having .95 alpha coefficients with a five-point response category were used to assess the quality of life. It has been validated for assessing quality of life (Ansari et al., 2014). To measure depression, anxiety and stress, The Depression, Anxiety and Stress Scale comprising twenty-one items having an alpha value of .84 with 5 points Likert ranging from where (1) (strongly disagree) to 5 (strongly agree) was used. It has been utilized in many cross-cultural investigations. The Pakistani population has formally validated DAS.

Results

In the current study, the data of 180 caretakers of thalassemia patients (female n =84, male n =96) have been analyzed. Concerning the prevalence rate of mental health-related issues, it was found that caretakers belonging to the nuclear family system experience more depression, anxiety, and stress and have a lower quality of life than caretakers with the joint family system.

Figure 1

Metal Health Issues and Quality of Life

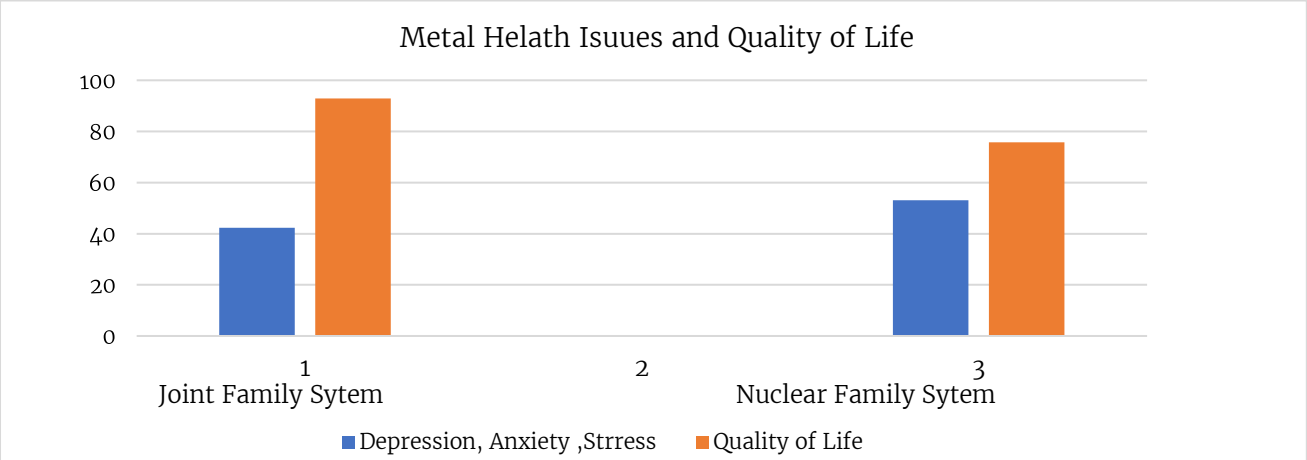

Table 1

Correlation Coefficient between Depression Anxiety Stress Scale and Quality of Life Scale (N = 180)

Measures	1	2	M	SD
1. DASS	-	-.275**.	52.05	7.29
2. QOL	-	-	94.18	6.93

Note: DASS= depression anxiety stress scale, QOL= Quality of life Scale *p <. 05

Results in Table 1 show that a significant negative association exists (r = -.257, p <.05) between the quality of life and mental health-related issues.

Table 2

Mean, standard deviation, and t-values scores of male and female caretakers on the Center for Depression, Anxiety, Stress Scale, and Quality of Life Questionnaire (N=180)

Scales	Female (n = 84)		Male (n = 96)		t(178)	p	Cl 95%		Cohen's d
	M	*SD*	*M*	*SD*			LL	UL	
QOL	49.27	7.04	54.83	6.32	5.57	.00	-5.05	3.27	0.25
DASS	96.06	7.54	92.30	5.79	3.76	.00	-4.41	3.20	0.32

Note: QOL=Quality of life Scale, Short form, DASS = Depression Anxiety Stress Scale.

As illustrated in Table 2, male caretakers were significantly higher in quality of life (*M* =54.83, *SD* = 6.32) than the quality of life in caretakers (*M* =54.83, *SD* =6.32), *t* (178) = 5.57 p < .05. The study results have also shown that the level of mental health-related issues is in female caretakers were higher (*M* = 96.06, *SD* = 7.54) than the male caretakers (*M* = 92.30, *SD* = 5.79), *t* (178) = 3.76, p < .05.

Table 3

Mean, standard deviation and t-values scores of caregivers with the nuclear and joint family systems on Quality of Life And Depression Anxiety And Stress Scale (N = 180)

Scales	Nuclear (n = 78)		Joint (n=102)		t(178)	p	Cl 95%		Cohen's d
	M	*SD*	*M*	*SD*			LL	UL	
QOL	91.90	5.47	97.16	7.15	5.51	.000	-5.05	3.27	0.25
DASS	55.23	5.76	51.82	6.73	3.57	.000	-3.72	4.01	0.34

Note: QOL=Quality of life Scale, Short form, DASS = Depression Anxiety Stress Scale.

As shown in Table 3, the level of mental health-related issues was higher in caretakers belonging to the nuclear family system (*M* = 55.23, *SD* = 3.57) than the level of depression in care those belonging to the joint family system (*M* =51.82, *SD* = 6.73), *t* (178) = 6.73, p < .05. Similarly, caretakers from joint family system experience higher quality of life (*M* = 97.16, *SD* = 7.15) as compared to caretakers belonging to nuclear family system students (*M* =91.90, *SD* = 5.47), *t* (178) = 5.51 p < .05.

Discussion

The present study had two objectives: to investigate the association between mental health-related issues and quality of life among caregivers of thalassemia patients and to explore the gender and family system-based differences in mental health and quality of life among the sample caretakers of thalassemia patients. Study findings showed that mental health-related issues have a significant negative association with quality of life. Results are in line with several studies, confirming the significant negative correlation between quality of life and mental health-related issues, i.e., depression, stress, and anxiety (Hafeez et al., 2023; Rikos et al., 2021). Consistent with the results of the current study, it was proved that an inverse correlation exists between depression, stress and anxiety, and quality of life among thalassemic caretakers (Angane et al., 2022). In another study, a negative relationship between stress, depression, anxiety, and quality of life was shown (Mitra et al., 2021).

The statistical analysis of the present study demonstrated considerable gender base differences exist in depression, stress and anxiety, and quality of life scales. These results show that females exhibit more depression and poor quality of life than male caregivers (Askaryzadeh et al., 2023). This finding is consistent with the findings of another study demonstrating that females scored higher on the depression scale than males (Sharma et al., 2016). The result of our study is consistent with another study which observed that females have the propensity to encounter more health-related issues (depression, stress and anxiety) and exhibit a poorer quality of life than males (Sevinç et al., 2023), female caretakers exhibit more depression and anxiety symptoms. The results of our study are consistent with the previous research at hand. Similarly, family system-based differences were observed in depression, stress, and anxiety. Consistent results were reported by suggesting that families observing the nuclear family system tend to experience more psychological burden and stress (Prajapati et al., 2021).

Based on current study results, it is presumed that a negative correlation exists between mental health-related issues and quality of life, and concerning gender and family system, significant differences exist in study variables among caretakers. An inverse relationship exists between mental health-related issues and quality of life among caretakers of thalassemic patients. The current study can be effective in realizing the psychological health-related problems experienced by caretakers of thalassemic patients concerning gender and family system-based differences in the association between psychological health-related issues and quality of life.

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