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Original Article

Prevalence of Psychological Distress among Mothers of β-Thalassemia Children in a Developing Country

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ABSTRACT

Beta-thalassemia major (BTM) is one of the most common hereditary hemoglobinopathies in Pakistan, with 9.8 million persons in the general population and gene carriers (5-7%). The mothers of these chronically ill patients often endure many challenges associated with caregiving. **Objective:** To determine the prevalence of psychological distress experienced by mothers of children suffering from BTM in a developing country. **Methods:** From March 2022 to August 2022, this descriptive cross-sectional study was done among mothers of thalassemic children who presented to the Outpatient Department of Benazir Bhutto Hospital in Rawalpindi. A self-structured questionnaire consisting of 1) Socio-demographic characteristics and 2) the Kessler-10 (K-10) Distress Measure was used to collect data. To determine the level of psychological distress among mothers of children, a descriptive analysis was done. The Spearman correlation was used to explore the relationship between demographic factors and the level of psychological distress experienced by mothers of children with thalassemia. **Results:** The mean age of mothers being interviewed was 37.65±3.63 years. Out of 83 mothers, 54(65.1%)had psychological distress. The children's age(r=-.275)and any psychological support taken by mother(r=-.253)were correlated(p<.05)negatively with the severity of psychological distress. **Conclusions:** Our study identified that most mothers of children suffering from thalassemia had psychological distress. Thus, these mothers are at risk of poor health outcomes and should be targeted for screening and treatments focused on improving their health and well-being.

INTRODUCTION

In thalassemia, a genetically transmitted disease, the production of hemoglobin (Hb) globin chains is primarily affected. The Southeast Asia, the Mediterranean, the Middle East and the Indian subcontinent, are all notable regions where this illness is a significant public health concern [1]. Beta-thalassemia major (BTM) is one of the most common hereditary hemoglobinopathies in Pakistan, with 9.8 million persons in the general population and gene carriers [2]. In the Pakistani population, the estimated carrier frequency for beta-thalassemia is 6% [3]. There are over 50,000 individuals enrolled at different treatment facilities across the nation. An estimated 100,000 children in Pakistan are transfusion-dependent thalassemia, and children born with the disease continue to increase this number by 7000–9000 each year [4, 5]. The parents of these chronically ill patients often endure many challenges associated with caregiving. The parental responsibilities of caring for a chronically ill child, combined with natural worry and financial woes, may be distressing. for many parents [6]. Generally, it is diagnosed at birth or within the first six to twelve months of life; therefore, mothers are the ones that are specifically involved [7]. These mothers have

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a variety of responsibilities, including looking for the child while receiving blood transfusions and Dysfral, looking after during many hospital stays, meeting the needs of the child with various thalassemia abnormalities, and monitoring various child testing [8]. According to Piran *et al.*, moderate-to-severe levels of care stress was reported by 49% of the mothers of children diagnosed with BTM [9]. Fears and concerns about the disease's progression, and apprehensions over the child's future are the mothers' most pressing psychological problems and conflicts [10]. Saldanha concluded that about 1.5% of the mothers, during the first two-years of child's therapy endure various psychosomatic-illnesses and require the assistance of others to continue treating the child [11]. A child with thalassemia needs special care from their mothers. It is a constant source of distress for the mothers, as their children must undergo the rigorous cycles of recurrent transfusions and iron chelation therapies. Almost 10-years is the average life expectancy among such patients, further adding fuel to the fire for the mothers, who are already concerned about the future of their children [12]. The majority of the literature has focused on the psychological effects of this condition on children's mental health, but there is very little information available that highlights the psychological discomfort experienced by mothers of children with thalassemia. Thus, our study aimed to determine the prevalence of psychological distress experienced by children's mothers in a developing country.

METHODS

From March 2022 to August 2022, this descriptive cross-sectional study was conducted among mothers of thalassemic children presenting in the Outpatient Department of Benazir Bhutto Hospital, Rawalpindi, using a self-structured questionnaire. Mothers of children with diagnosed BTM aged less than 15 years were included in this study. Before starting the interview, a form requesting their informed permission was given to and signed by each participant. The questionnaire had two parts 1) Socio-demographic characteristics and 2) the Kessler-10 (K10). Sample size was calculated using WHO sample size calculator 1.1. The sample size was found to be 61 taking population proportion of beta-thalassemia 6%, absolute precision of 6% and confidence interval 95% [3]. A total of 100 mothers were interviewed, out of which 83 mothers met the criteria and were included in this study. Socio-demographic details included children's age and gender, marital status, any psychological support taken, and the number of children with thalassemia in the family. The Kessler-10 (K10) was used to assess psychological distress. The US National Health Interview Survey designed this 10-item, self-administered questionnaire [13]. Based on questions about anxiety and depressive experiences encountered in the most recent 30-day period, it is intended to provide a global measure of psychological distress. Responses range from "none of the time" to "all of the time" on a 5-point Likert scale for each item. The sum of these 10 questions yields a composite score; higher scores suggest more psychological discomfort. [13]. K-10 scores were further subdivided into comparable levels of psychological distress, with a score under 20, a score 20-24, a score 25-29, and a score 30 or more indicating, respectively, no mental distress, a mild mental distress, a moderate mental illness and a serious level of distress. This questionnaire has Cronbach's alpha value of 0.705, indicating reasonable internal consistency. Frequencies and percentages were used to describe socio-demographic factors. A descriptive analysis was done to determine the levels of psychological discomfort experienced by mothers. To evaluate the relationship between demographic factors and psychological distress experienced by mothers of thalassemia-affected children, Spearman correlation was performed. The IBM Statistical Package for Social Sciences (SPSS) version 23.0 was used to analyze the data. A two-tailed $p < .05$ was defined statistically significant.

RESULTS

A total of 83 mothers were included in this study and the mean age of mothers being interviewed was 37.65±3.63 years. Majority 78.3% of the participants were unemployed. A sum of 24(29%) reported more than one child suffering from BTM. Table 1 shows demographic characteristics of participants.

Characteristics		N (%)
Child's age (mean±SD)	10.92±2.13	
Gender	Male	58 (69.9%)
	Female	25 (30.1%)
Mother's age (mean±SD)	37.65±3.63	
Single parenting	yes	17 (20.5%)
	No	66 (79.5%)
Employed	yes	18 (21.7%)
	No	65 (78.3%)
Any psychological support taken	yes	9 (10.8%)
	No	74 (89.2%)
Number of children with thalassemia in family	One child	59 (71%)
	More than one	24 (29%)

Note. N: Frequency; %: percentages; SD: Standard deviation.

Table 1: Demographic characteristics of participants (n=83)

In this study, 54 (65.1%) mothers had psychological distress. On the other hand, only 29(34.9%) mothers were well according to K10 questionnaire interpretation. Table 2 shows the psychological distress encountered by the mothers of children diagnosed with thalassemia.

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Distress	N (%)
Well	29 (34.9%)
Mildly unwell	22 (26.5%)
Moderately unwell	19 (22.9%)
Severely unwell	13 (15.7%)

Note. N: Frequency; %: percentages

Table 2: Distribution of Psychological Distress among mothers (n=83).

DISCUSSION

Researchers have long been interested in the well-being and quality of life of mothers taking care of their children with chronic illnesses. The mother's anguish and pain are often felt in tandem with the child's suffering. In our study, it was found that 54(65.1%) mothers were suffering from psychological distress. A study by Zolaly *et al*. concluded that stress symptoms were detected in 38.7% of patients [14]. However, in this study, both parents were included, while our study included mothers only. On the other hand, Ali S *et al*. reported psychological stress to be 60% among caregivers [15]. In a study done in Malaysia, psychological distress was present in nearly half of the parents of children with transfusion-dependent thalassemia(42%, n= 68) [16]. In our study, there were 69.9% male and 30.1% female children; Humaira Y. and Shahida H. also reported similar results. In their study, the majority (65.5%) had just one kid with BTM, but in our study, comparable results were obtained 59 (71%) [5]. In our study, the mean child's mean age was 10.92±2.13 years, while a study done in Pakistan documented 10.71±1.99 years [17]. The mean age of our caregivers was 37.65±3.63 years, similar to research conducted in Rawalpindi. According to our study, mild distress affected 26.5%, moderate distress affected 22.9%, and severe distress affected 15.7% of mothers. While a study conducted in Pakistan reported that among the caregivers mild, moderate and severe distress was found in 10 (20.8%), 13 (27.1%) and 25 (52.1%) mothers respectively [18]. Ankush *et al*. found that out of 7 mothers, 4 (57.14%) were psychologically affected by the chronic illness of their thalassemia children [19]. Similar to our findings, research carried out in India and a Greek transfusion center found no significant correlation between stress and the gender of patients and caregivers [1, 20].

CONCLUSIONS

Our study identified that most mothers of children suffering from thalassemia had psychological distress. Thus, these mothers are at risk of poor health outcomes and should be targeted for screening and treatments focused on improving their health and well-being.

Conflicts of Interest

The authors declare no conflict of interest.

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