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Research Article

Exploring Caregiver Burden of Thalassemia Major Patients

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Abstract: Thalassemia requires lifelong therapy that continuously strains patients, their families, and the local health system. This study was designed to analyse the challenges faced by carers and the effect they have on their social, psychological, and personal lives. Two hundred parents (100 cases and 100 controls) were recruited. In addition to socioeconomic status and concerns, feelings about children and their state of depression were also recorded by the PHQ-9 instrument. Statistically significant correlations were found which showed that parents are exposed to trauma at a very early age which limits their ability to become effectual individuals. Therefore, training and counselling must be worked out with extended family members for whom the health care body should also play its part in alleviating their sufferings. Overall, this study emphasized the significance of considering caregiver worries regarding improving the well-being of children.

Keywords: Thalassemia, Depression, Genetic Counselling, Extended Family Screening, PHQ-9.

1. INTRODUCTION

Thalassemia is the most prevalent monogenic illness, with an approximately 270 million carriers of hemoglobinopathies worldwide [1]. It is characterized by persistent anemia, hepatosplenomegaly, bone abnormalities, particularly of the facial bones, and an abnormal growth rate. Iron chelation therapy and routine blood transfusions become necessary for lifelong administration [2]. Due to absence of any proper registry for thalassemia in Pakistan, exact carrier rate is unknown but various reports have shown a carrier rate of approximately 5-7% [3, 4]. Unfortunately, among the WHO member states in the Eastern Mediterranean Region (EMRO), Pakistan had the greatest risk of thalassemia [5]. Consanguineous unions, huge populations with high birth rates, and ineffective preventive efforts are all regarded as major threat variables. A lack of awareness is also linked with high risk, which is dictated by illiteracy, social as well as cultural structure and religious preferences [2]. In modern society, parents are frequently obligated to provide for their children's needs, from blood transfusions to pharmaceuticals. The difficult routine and seeing a child in declining health have a negative impact on the caregiver [6]. The perceived impact of caregiver tasks on the caregiver's own sentiments and possessions is known as caregiver burden. It is a multifaceted concept that includes objective burden, subjective demand burden and subjective stress burden. While subjective demand burden refers to the interpersonal burden between carer and care recipient, objective burden refers to the interference with personal and social life. The emotional strain that the caregiver feels as a result of societal intolerance, self-blame for bad kid circumstances, improper responses, and reluctance to partake in social activities is known as the subjective stress burden [7].

The parents' primary concerns include their children's suffering, financial insecurity, and fear for their children's future [8]. As a result, understanding the causes of poor quality of life will aid in the development of appropriate methods of parent counselling. However, people use

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various coping mechanisms to manage their stress. However, further research is needed in this area to uncover difficulties underlying the failure of coping techniques [7, 9]. All difficulties experienced by caregivers' in caring for a thalassemic kid are influenced by a variety of factors and variables. The hidden facets of these experiences can be explored by employing the conventional questionnaire-based study. In this regard, this study was designed to analyse their experiences caring for the patient as well as their perceptions regarding sickness.

2. METHODOLOGY

2.1. Subject Selection

For this case-control study, subjects were enrolled by a non-probable convenient sampling method from December 2012-13. Only parents who took their children to transfusion centres on a regular basis were asked to participate in this study on weekdays between the hours of 9 a.m. and 4 p.m. The following criteria were required for inclusion: (1) parent of no less than one kid with thalassemia, (2) registration at the corresponding transfusion centre, (3) willingness to contribute, and (4) neither a physical nor a mental defect. Exclusion criteria included: (1) being a family member or guardian of a kid with thalassemia, (2) not being completely involved or oriented in child therapy, (3) being unwilling to participate, and (4) having a depressive condition, physical or mental abnormalities, or prolonged mental health condition. An informed consent was obtained after giving a brief summary about study objectives and guaranteeing the confidentiality of provided information. Participations were offered no compensations and they can voluntarily discontinue at any time. One hundred cases at transfusion centre and 100 cases at home as control were enrolled. Among 200 subjects, 21 unfinished questionnaires and 04 voluntary terminations cut down the number to 175 including 83 cases and 92 controls. Data were collected over the course of 15-20 minutes depending on each participant's response at the transfusion centre for cases and at home for controls.

2.2. Data Collection

The information was obtained in three parts: the PHQ-9 instrument (9 questions about depressive indicators), psychologically suitable skills (especially emotion, data, as well as sustenance), along with sociodemographic information. Five mothers were shown the questionnaire with thalassaemic children in order to ensure that it was obviously implied. The questionnaire was prepared more comprehensible by detailing in Urdu language whenever possible. The PHQ-9 questionnaire was used to assess depression severity. It utilizes the contents of the Diagnostic and Statistical Manual, Fourth Edition (DSM-IV) [10], major depressive disorder diagnostic criteria. It has nine questions, and the findings were classified on a 4-point Likert scale from 0 to 1, reliant on the length of the indicators that had lasted during the previous one month. Data were encoded as: 0 = not at all, 1 = several days/months, 2 = half days/month and 3 = daily. Depending on the scores, the intensity of depression was rated into 5 rankings calculated such as: 1-4 = minimal depression, 5-9 = mild depression, 10-14 = moderate depression, 15-19 = moderately severe depression and 20-27 = severe depression. Higher the score, sever will be the condition [8-11].

In addition, a questionnaire created on previously deliberated studies was employed. The emotional sphere contains information regarding parents' feelings when they learned about their child's illness and their emotions regarding their caregiving practice. The next domain included questions about understanding of parental sickness, carrier testing, patterns of inheritance, and management. The third domain takes into account social and societal assistance as well as future financial stability in the wake of this tragedy. Their demographic factors were gender, age, marital status, occupation, age at marriage, thalassemia family history, number of affected children, prenatal screening, carrier confirmation prior to marriage and death from thalassemia [9, 11].

2.3. Data Analysis

The data was analysed through descriptive and analytic statistics in SPSS version 20.0. Descriptive statistics were used to determine the means and frequencies of demographic parameters. Difference between the two groups was determined by independent sample t test. Significant determinants were determined by Pearson's correlation.

3. RESULTS

3.1. Sample Characteristics

Two hundred participants were enrolled in this study. Twenty-seven participants (19 from cases and 08 from control) discontinued the questionnaire. They were given the option to resume and only two continued it again while 25 refused to continue. The final number were 175 participants (83 cases and 92 control). The demographic characteristics of 175 members are presented in Table 1. The 91 (52%)

Table 1. Baseline parameters of study participants.

Characteristics of participants	Total	n (%)		P-value
		Cases	Control	
Gender		83	92	
Male	84	40 (48.2)	44 (47.8)	0.599
Female	91	43 (51.8)	48 (52.2)	
Respondents' relationship				
Father	84	40 (48.2)	44 (47.8)	0.599
Mother	91	43 (51.8)	48 (52.2)	
Age (Years)				
15-25	38	21 (25.3)	17 (18.5)	0.002
26-35	85	29 (34.9)	56 (60.9)	
<35	52	33 (39.8)	19 (20.7)	
Average (Years ± SD)		31.4 ± 7.2	31.7 ± 4.2	
Marital status				
Married	137	62 (74.7)	75 (81.5)	0.522
Separated	19	11 (13.3)	08 (08.7)	
Widow	19	10 (12)	09 (09.8)	
Consanguine marriage				
Yes	109	57 (68.7)	54 (58.7)	0.098
No	66	26 (31.3)	38 (41.3)	
Age at marriage				
15-25 Years	93	46 (55.2)	47 (51.1)	0.006
26-35 Years	73	28 (33.7)	45 (48.9)	
<35 Years	9	09 (10.8)	-	
Average (Years ± SD)		25.7 ± 4.8	25.9 ± 2.6	
Employment status				
Businessman	9	03 (3.6)	06 (6.5)	0.08
Employed	55	22 (26.5)	33 (35.9)	
Daily wedges	44	28 (33.7)	16 (17.4)	
Jobless	67	30 (36.1)	37 (40.2)	
Level of education				
Illiterate	31	25 (30.1)	06 (6.5)	<0.000
Under-matric	15	09 (10.8)	06 (6.5)	
Matric	60	22 (26.5)	38 (41.3)	
Intermediate	36	22 (26.5)	14 (15.2)	
≥Graduate	33	05 (06)	28 (30.4)	
Family income				
<8000 PKR	21	11 (13.3)	10 (10.9)	0.185
8000-16000 PKR	98	49 (59)	49 (53.3)	
17000-24000 PKR	51	21 (25.3)	30 (32.6)	
≥25000 PKR	05	02 (02.4)	03 (03.3)	
Heard of thalassemia before				
Yes	50	31 (37.3)	19 (20.7)	<0.000
No	125	52 (62.7)	73 (79.3)	

of the participants (mothers) were female, and their percentage was highest for both studies: cases 43 (51.8%) as well as controls 48 (52.2%). Mean age of the cases and control were 31.4 ± 7.2 and 31.7 ± 4.2 respectively. However, in cases most were above 35 years of age 33(39.8%) and in controls were 26-35 years of age 56 (60.9%).

The majority were married, with 62 (74.7%) in cases and 75 (81.5%) in controls. Consanguine marriages were most likely appearing in both cases 57 (68.7%) as well as controls 54 (58.7%). About 67 (38%) were unemployed, although the majority were women and housewives. Literacy rates were lower in cases than in controls, with 25 illiterates (30.1%) in cases and 6 illiterates (6.5%) in controls. The financial well-being was also compromised in both cases and controls. 21 participants (11 cases and 10 controls) earned less than 8000 PKR per month, whereas just five participants (02 cases and 03 controls) earned more than 25000 PKR per month. As seen in the control group 73 (79.3%), the majority of the population in general is still unaware of thalassemia. More than half of the patients, 52 (62.7%), had not heard of thalassemia prior to their child's diagnosis. At a significance level of 0.05 in cases and controls showed significant associations for age (0.002), age at marriage (0.006), level of education (<0.000), and prior knowledge of thalassemia (<0.000).

3.2. PHQ Scores

PHQ scores that were computed for patients and controls represented in Table 2. At a significance level of 0.05, a significant correlation was found (<0.000). In the control group, none of the subjects scored severely depressed (<14) and number of subjects with moderate depression, 01 (1.1%) was lower as compared to the number in cases 22 (26.5%).

3.3. Feelings Associated with Caregiver Burden

Data represented in Table 3 shows that 31.3% of the 83 cases had a prior thalassemia diagnosis. However, the majority of the parents 59 (71.1%) had only one kid with thalassemia, and the majority were females 47 (56.6%). 17 (20.5%) people indicated that their child died as a result of thalassemia. It was quite distressing that 59 (69.9%) of the parents were uninformed of the nature of thalassemia their kids had. Though, they were all informed of the length of time needed to complete every transfusion. Every two months, about 36 (43.4%) patients required more than three transfusions.

Parents' feelings about the diagnosis and subsequent treatments were also questioned. When asked how they felt when they learned about their child's illness, 31 (37.3%) expressed sadness. However, 16 (19.3%) mentioned stigmatization fear. When asked about experience as caregiver 48 (57.8%) and adjustment to the circumstances 76 (91.06%) most answered positively. Only 32 (38.6%) of the 83 instances studied avoid asking children questions about their treatment effects, duration of existence as well as social life discrimination.

According to the findings of this study, 45 (54.2%) of participants were uninformed about the techniques of diagnosis while 76 (91.6%) did not undertake carrier testing. Nevertheless, 20 (24.1%) of them missed a close carrier testing laboratory and females lacked awareness at the beginning of their diagnosis. Despite this, 41 people who had a thalassaemic child did not seek prenatal diagnosis. However, more than half reported knowing insufficiently 24 (28.9%) or not understanding 20 (24.1%) the disease's process. Additionally, it was discovered that 55 (66.3%) patients were dissatisfied

Table 2. PHQ-score in cases and controls.

PHQ scale	**Total**	**n (%)**	
States of depression		**Cases**	**Control**
Minimal	56 (32)	05 (6)	51 (55.4)
Mild	92 (52.6)	52 (62.7)	40 (43.5)
Moderate	23 (13.1)	22 (26.5)	01 (1.1)
Moderately severe	3 (1.7)	03 (3.6)	-
Severe	1 (0.6)	01 (1.2)	-
Mean score ± SD	-	8.43 ± 3.2	4.61 ± 2.3
P-value	<0.000		

with the medical advice given since it was either inadequate or hard to fully understandable. Positive support was reported by parents from their spouse 53 (63.9%), family 56 (67.5%), society 60 (72.3%) and health personnel 57 (68.7%). Though, 69 (83.1%) of case respondents reported that their financial situation had deteriorated since their child's illness and subsequent treatment. Half of the participants, 42 (50.6%), were more enthusiastic about learning about the course of action and eventual results, while 27 (32.5%) desired to know more about the disease. Univariate analysis results shown in Table 3 revealed that with the exception of fear of stigmatization, spousal support, and thalassemia information, all other characteristics were substantially linked with poor psychosocial state of thalassemic caregivers.

4. DISCUSSION

This study aimed to emphasize the risk and contributing variables for caregivers of thalassemic children. Participant replies underlined the mothers' demands and concerns, which were replicated in prior investigations [9]. Thalassemia impacts not only those children suffering from it but the entire family in the long run [12]. Previous research defined a caregiver as someone who cares for a chronically ill individual for free [11]. Thalassemia is a chronic condition with no long-term treatment, elevates parental concerns regarding puberty delay, body image, frequent absences from school, uncertainty regarding the future which involves career building as well as marriages along with fear of death, making them susceptible to psychological pain at a young age in life. All of this impedes their development into self-sufficient functional adults [2, 12].

The difference in depression severity among nations is influenced by social and environmental factors. Anum and Dastagir [12] previously discovered a connection between the severity of the medical condition and the mother's depression. Depression in caregivers can be associated with their lifestyle. For instance, lack of leisure activities, fewer visits to family and friends, and an unsatisfied mind are all factors that contribute to caretaker depression. Regular transfusions are another factor contributing to the parents' concern and distress. In contrast to earlier studies, participants expressed uncertainty regarding their children's futures, particularly their marriage and careers. They were optimistic about their children's future [13].

Due to the thalassemic child, parents were separated in a few cases 11 (33.3%). Every day presents fresh challenges to a caregiver. Early disease onset and ongoing therapy increase parental pressure at an early age. Aside from disease, the caregiver puts a hardship on other children by devoting time to the affected child. Stress can be enhanced more by enduring anger, regret and humiliation from family members. This issue may be overcome by learning to be patient and generous as well as self-disciplined in the manner to organize their spare time, establish goals, and put forth efforts to achieve them [9].

The problem with our society is that thalassemia-affected children are not accepted. They are stigmatized more frequently, which demoralizes not just the youngster but also rest of the family. Frequent absences from school place the youngster behind in their academics, which is misinterpreted as a lack of cognitive capacities, resulting in a low learner [13]. Furthermore, direct questions from the affected youngster concerning his/her health, profession, marriage, or death operate as a stress stimulant for the caregiver. In some cases, it is preferable to keep the children informed of their health state so that they can take a more active role in their care. In previous investigations, it was found that lower education was linked to worse caregiver outcomes while being female was not a factor [14, 15].

One more serious concern that increased thalassemia's burden was financial concerns. The main cause of an increasing burden on families was an increase in the expenditures of living, transportation, and admittance. Similar results have been obtained in earlier research. Despite the fact that transfusions are free, the cost of transportation and leaving a regular job or place of employment to visit a transfusion clinic can be both mentally exhausting and financially draining [8, 13, 16].

It should be mentioned that such feelings do not occur overnight, but rather as a result of their continual care for their impaired child. This may be caused by a variety of circumstances, including the weakening of family support over time, stigmatization of mothers in particular regarding

Table 3. Psycho-functional capabilities of caregivers (n = 83).

Characteristics	n (%)	OR	*p*-value
Family history			
Yes	26 (31.3)	Ref.	
No	57 (68.7)	4.8 (2.4-9.26)	<0.0001
Number of thalassemic child			
1	59 (71.1)	79.7 (18.3-346.5)	<0.0001
2	22 (26.5)	14.6 (3.3-64.5)	0.0004
3	02 (02.4)	Ref.	
Gender of thalassemic child*			
Male	36 (43.4)	Ref.	
Female	47 (56.6)	1.7 (0.9-3.14)	0.08
Birth order of thalassemic child*			
1	50 (60.2)	29.9 (10-89.5)	<0.0001
2	29 (34.9)	10.6 (3.5-31.9)	<0.0001
3	04 (04.8)	Ref.	
Death of thalassemic child*			
Yes	17 (20.5)	Ref.	
No	66 (79.5)	15 (7-32)	<0.0001
Thalassemia type			
Known	25 (30.1)	Ref.	
Unknown	58 (69.9)	5.4 (2.7-10.4)	<0.0001
Transfusion frequencies			
2/8 weeks	21 (25.3)	Ref.	
3/8 weeks	26 (31.3)	1.3 (0.68-2.65)	0.39
≥ 4/8 weeks	36 (43.4)	2.3 (1.17-4.4)	0.02
Related to Feelings			
Feeling at time of diagnosis			
Shocked	26 (31.3)	3.3 (1.48-7.46)	0.004
Anger	10 (12)	Ref.	
Sorrow	31 (37.3)	4.4 (1.96-9.65)	0.003
Fear of stigmatization	16 (19.3)	1.7 (0.7-4.1)	0.203
Experience faced as caregiver			
Frustrated	35 (42.2)	Ref.	
Non-frustrated	48 (57.8)	1.8 (1-3.5)	0.04
Avoids children question			
Yes	32 (38.6)	Ref.	
No	51 (61.4)	2.5 (1.36-4.75)	0.004
Adjusted with the circumstances			
Yes	76 (91.6)	Ref.	
No	07 (8.4)	117 (39.4-352)	<0.0001
Related to Information			
Carrier testing			
Yes	07 (8.4)	117 (39.4-352)	<0.0001
No	76 (91.6)	Ref.	
Why not consult doctor at time of pregnancy			
Don’t know	45 (54.2)	4.3 (2.17-8.4)	<0.0001
Normal pregnancy	18 (21.7)	Ref.	
No facility available	20 (24.1)	1.15 (0.56-2.4)	0.71
Prenatal screening after thalassemic child			
Yes	19 (22.9)	Ref.	
No	41 (49.4)	3.3 (1.7-6.4)	0.0005
NA	23 (2.7)	1.2 (0.6-2.6)	0.48
Information about thalassemia			
Insufficient	24 (28.9)	1.2 (0.64-2.56)	0.48
Moderately sufficient	12 (14.5)	0.5 (0.24-1.18)	0.12
Don’t understand	27 (32.5)	1.5 (0.77-3)	0.23
Continuous process	20 (24.1)	Ref.	
Guidance from physician			
Insufficient	38 (45.8)	3.3 (1.65-6.5)	0.0007
Moderately sufficient	28 (33.7)	1.98 (0.98-3.98)	0.057
Don’t understand	17 (20.5)	Ref.	

Related to support received				
Support from spouse				
	Yes	53 (63.9)	16.6 (7.04-39)	<0.0001
	Busy with job	08 (09.6)	Ref.	
	End up in sorrow or quarrel	02 (02.4)	0.23 (0.048-1.13)	0.07
	Not alive	20 (24.1)	2.98 (1.23-7.22)	0.02
Support from family				
	Most of the time	56 (67.5)	64.9 (18.6-226.8)	0.3
	Not always available	19 (22.9)	7.9 (2.24-27.9)	<0.0001
	Stigmatization	05 (06)	1.71 (0.39-7.4)	0.473
	Continuous support	03 (03.6)	Ref.	<0.0001
Support from society				
	Yes	60 (72.3)	6.8 (3.4-13.4)	<0.0001
	No	23 (27.7)	Ref.	
Support from health care staff				
	Mostly supportive	57 (68.7)	Ref.	
	Insufficient	06 (07.2)	28.1 (10.86-72.86)	<0.0001
	Biased	08 (09.6)	0.048 (0.02-0.115)	<0.0001
	Didn't notice	03 (03.6)	0.02 (0.005-0.06)	<0.0001
	Sufficient	09 (10.8)	0.06 (0.02-0.128)	<0.0001
Financial status after disease diagnosis				
	Same as before	14 (16.9)	Ref.	
	Lower than before	69 (83.1)	24.3 (10.8-54.7)	<0.0001
Need				
	Emotional control strategy	11 (13.3)	Ref.	
	Information about disease	27 (32.5)	3.16 (1.4-6.9)	0.004
	Time to discuss about treatment and its outcomes	42 (50.6)	6.7 (3.1-14.4)	<0.0001
	Nothing needed	03 (03.6)	0.25 (0.06-0.91)	0.036

OR = odds ratio, Ref. = referent category, values in brackets are range. *P value* ≤ 0.05 was considered significant.

their children's health, and the progression of the illness. In this way family support is insufficient due to excessive demands [17].

It is impossible to overestimate the importance of psychological therapy, as it will have a long-lasting influence on caregiver as well as family along kid [2]. Thalassemia is an illness that requires lifelong care, putting a persistent strain on individuals, their families, and the territory's health organization. Parents may experience unnecessary anxiety and mental discomfort due to the lack of awareness regarding thalassemia and its management [12]. Such details ought to be repeated at regular periods. Doctors and other health care providers can help mothers and their children by incorporating psychological support into their care plans for thalassemic patients [5, 7].

Despite having a positive family history, consanguine marriages are common in a small number of families which contributes to the failure of thalassemia prevention efforts. Due to low literacy rates, parents were not well-informed on the nature of the illness, inheritance patterns, and course of treatment. These issues rise questions that include how mutations happen, why people need transfusions for the rest of their lives, and which medical interventions work best. This knowledge should be reinforced at predetermined intervals, especially while giving medicinal treatments [7, 17]. This requires healthcare professionals particularly doctors to take a role in spreading their message. As a result, educational programs based on parents' educational needs, socioeconomic situation, educational level, gender as well as age are highly recommended. This plan of actions should also be available to the extensive families of present patients. Furthermore, support from a spouse along with family members assisted in lowering the psychological strain linked to thalassemia [2, 18].

To end the misconception that thalassemia is a contagious disease, as well as the acceptance of pre-screening along with premarital exams and unfavourable rejection letters for family members screening due to stigmatisation fears, a physician's responsibility in a community-based awareness campaign must be initiated, in addition to ethical principles and cultural norms. The large number of case individuals with low-income backgrounds may restrict the trustworthiness of our findings. The

poorer psychological condition might be related to the time spent during the transfusion period [19].

5. CONCLUSIONS

Caregivers of thalassemia are exposed to trauma in their very early age that limits their ability to become effectual individuals. Parental anxiety and emotional discomfort might be unintentionally intensified by their lack of understanding of thalassemia and its treatment. As a result, offering comprehensive and appropriate health treatments to these caregivers along with psychiatrist nurses in assisting them to resolve the psychological challenges is valuable. Additionally, promoting caregivers awareness of self-care and manners to care for children with illnesses, establishing periodic educational programs for other family members and close relatives of thalassemia patients, setting up private institutions with the public's involvement despite imposing financial burdens on families, and promoting public awareness about thalassemia through media are all essential. All these strategies must be built considering the parental educational needs, financial status, academic achievement, age as well as gender in order to maintain the health status of caregivers and child with illness.

6. ETHICAL STATEMENT

This study was approved by ethical committee of School of Biological Sciences, the University of the Punjab, Lahore, Pakistan. The mentioned work was done in conformity with the World Medical Association's Code of Ethics (Declaration of Helsinki).

7. CONFLICT OF INTEREST

Authors have no conflict of interest.

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