

Anxiety and Depression among Caregivers of the Children with Thalassemia, Attending at Thalassemia Control Unit of a Rural Tertiary Care Medical College, Darjeeling, West Bengal

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Abstract

Background of Study: Caregivers of the children with thalassemia often experienced a life with varied degree of anxiety and depression due the chronic illness like of their children. Mothers as the main caregivers for most of the thalassemic children suffers with different forms of psychological problems. **Objectives:** The aim of this study was to assess the levels of anxiety and depression of the caregivers of children with Thalassemia and also to find out sociodemographic factors associated with their anxiety and depression. **Materials and Methods:** Descriptive cross-sectional study conducted in Thalassemia Control Unit (TCU) of North Bengal Medical College (NBMC) from December 2018 to April 2019. Complete enumeration method was used to include 136 caregivers of children (≤ 12 years) with thalassemia. Beck Anxiety Inventory (BAI) and Beck Depression Inventory (BDI) was used to assess the levels of anxiety and depression. Collected data were entered into MS-Excel and analyzed by using SPSS software program, version 22.0. **Results:** Mean age of caregivers was 34.3 (SD $\pm$ 1.4 years). Most of caregivers were female (89%) and had educational qualification up to primary school (45.6%). Majority (70.6%) of the caregivers were the mothers of the children. Most of the study participants (54.4%) had moderate depression followed by 30.1% with mild mood disturbances. Majority (69.9%) of the study participants had mild anxiety and 30.1% moderate anxiety. The median (IQR) of BDI score was 21(23–18) and median (IQR) of BAI score was 20(22–18). **Conclusions:** Early counseling, psychotherapy, appropriate treatment should be prioritized. Social support, community involvement with their full participation should be emphasized.

Keywords: Anxiety, caregivers, children, depression, Thalassemia

INTRODUCTION

Thalassemia is very much prevalent in Northern part of West Bengal among the ethnic group (Rajbanshi families). In this region of West Bengal among those with abnormal hemoglobin, 66% belonged to the Rajbanshis. There was statistically significant association ($P < 0.05$) between HbE syndrome and the Rajbanshi families.^[1]

The prevalence of thalassemia ranges between 2 and 25% Worldwide.^[2] For every 100,000 live births, approximately 4.4 children are affected by thalassemia globally.^[3]

The carrier rate for *b* -thalassemia varies from 1% to 17% with 10,000 children (one-tenth of the world) with *b* -thalassemia major is born every year in India.^[4,5] Every 10th person is a thalassemia carrier with more prevalent

among scheduled caste, scheduled tribe and Muslim populations in West Bengal.^[6]

Therefore, understanding the levels of anxiety and depression of the caregivers of children with Thalassemia is necessary which will help us to take appropriate measures to reduce their anxiety and depression and also to give them a better mental health.

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Usually, caregivers of the children with Thalassemia often experienced a life with varied degree of anxiety and depression due the chronic illness like Thalassemia, of their children. Mothers as the main caregivers for most of the thalassemic children suffers with different forms of psychological problems.

MATERIALS AND METHODS

Study design and setting

A descriptive, observational, cross-sectional study was conducted in the Thalassemia Control Unit (TCU) of North Bengal Medical College (NBMC) from December 2018 to April 2019.

Study population

All the caregivers of the children (≤ 12 years) suffering from Thalassemia who were attended Thalassemia Clinic of North Bengal Medical College (NBMC), were included as study participants. Participants with repeat visit, unwilling and the children who were more than 12 years were excluded.

Sample size and sampling technique

After applying exclusion and inclusion criteria, Complete enumeration technique was used and a total of 136 participants ($n = 136$) were included.

Data collection tools

Data were collected using Beck Anxiety Inventory (BAI) and Beck Depression Inventory (BDI) to assess the levels of anxiety and depression among the study participants. BAI is a self-reported questionnaire with 21 items with good reliability (Cronbach $\alpha = 0.92$ with test-retest reliability (1 week) is 0.75.^[7] BDI is self-scored questionnaire with 21 items with high 1-week test-retest reliability ($r = 0.93$) and Cronbach $\alpha = 0.91$. Lowest possible score is zero and highest possible score is 63.^[8]

The BAI and BDI was translated into Bengali from English and retranslated into English. The translated versions of the questionnaire were validated by different experts. Pretesting of the questionnaire was done for necessary modifications. The Bengali version of BAI and BDI was used for collection of data.

Data collection procedure

Prior intimation was given to the In-charge of Thalassemia Control Unit (TCU) of North Bengal Medical College (NBMC). Diagnosed thalassemic children attending to Thalassemia Clinic, were identified. Their caregivers were approached and informed about the purpose of this study. Only the willing study participants were included. Participants with repeat visit and children of age > 12 years were excluded. Full assurance was given to the participants about the confidentiality about their identity. Participants who were illiterate or faced any problems during filling

were assisted to fill out the questionnaire. Both self-administration and interview technique were used for collection of information. Demographic information was also collected. At the end all the participants were acknowledged for their kind cooperation.

Statistical analyses

Collected data entered into Microsoft-Excel software, double checked and analyzed using IBM SPSS software program, version 22.0. Frequencies, proportions, mean with SD, median with intra quartile range (IQR) were used for descriptive statistics.

In socioeconomic status (SES) class, as the percentage of SES class I and V were negligible, SES class I and II were clubbed into a single SES class (upper class) and SES class IV and V were clubbed into a single class (lower class). SES class III was considered as middle SES class for better interpretation of study results.

Ethical consideration

Approval was taken from the Institutional Ethics Committee of North Bengal Medical College, Darjeeling.

RESULTS

Mean age of caregivers was 34.3 (SD ± 1.4 years) [Table 1]. Most of caregivers were female (89%) and had educational

Table 1: Sociodemographic characteristics of the study participants ($n = 136$)

Variables	Number (%)
Age (in years)	
≤ 34	80 (58.8)
> 34	56 (41.2)
Sex	
Male	15 (11)
Female	121 (89)
Educational qualification	
Illiterate	12 (8.8)
Primary school	62 (45.6)
Middle school	43 (31.6)
High school and above	19 (14)
Relationship with the child	
Mother	96 (70.6)
Father	24 (17.6)
Grand mother	11 (8.1)
Grand father	5 (3.7)
Occupation	
Home makers	96 (70.6)
Others	40 (29.4)
Socioeconomic class*	
Upper class	23 (16.9)
Middle class	44 (32.4)
Lower class	69 (50.7)
Total	136(100)

*According to modified B.G. Prasad Scale (April 2019)

qualification up to primary school (45.6%). Majority (70.6%) of the caregivers were the mothers of the children. Approximately 70.6% of the study participants were homemaker by occupation. Majority (50.7%) belonged to lower socioeconomic class.

Table 2: Distribution of the study participants according to their levels of anxiety and depression (n = 136)

Category of anxiety (according to BAI score)	Frequency (%)
Low anxiety	95(69.9)
Moderate anxiety	41 (30.1)
Category of depression (according to BDI score)	
Normal to Mild mood disturbance	61 (44.9)
Moderate depression	74 (54.4)
Severe depression	1 (0.7)
Total	136 (100)

Majority (69.9%) of the study participants had mild anxiety and 30.1% moderate anxiety [Table 2]. Most of them (54.4%) had moderate depression followed by 30.1% with mild mood disturbances. The median (IQR) of BDI score was 21(23–18) and median (IQR) of BAI score was 20(22–18).

Box and Whisker plots showing the differences in median BDI Score among different sexes, socioeconomic classes, educational status of the study participants. Upper SES class were more depressed than lower SES Class [Figure 1]. Illiterate caregivers were less depressed than the caregivers who had the educational qualification of high school and above.

No statistically significant association was found in between sociodemographic characteristics of the study participants with level of anxiety [Table 3].

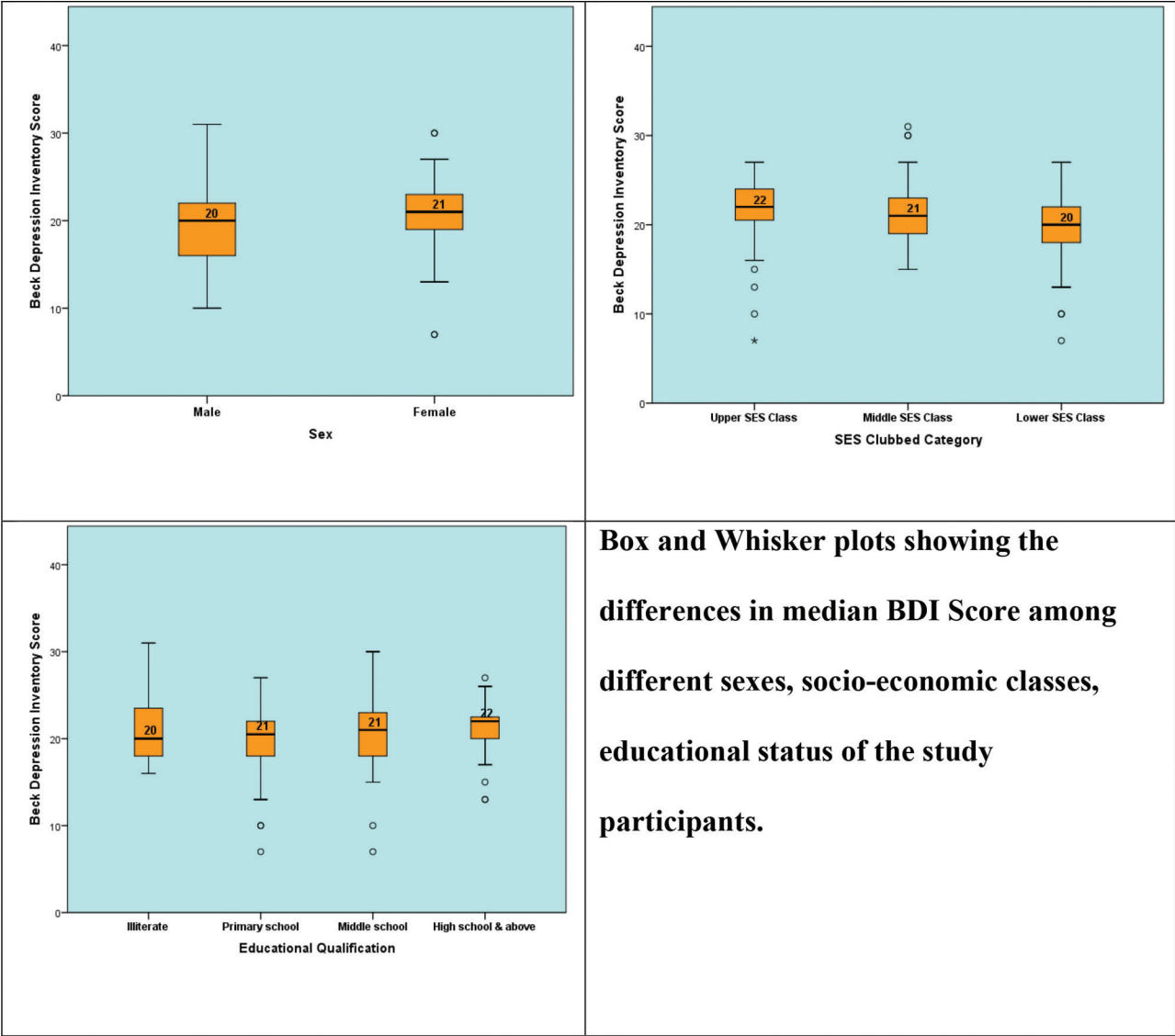


Figure 1: Box and Whisker plots showing the differences in median BDI score among different sexes, socioeconomic classes and educational status of the study participants

Table 3: Association of anxiety with sociodemographic characteristics of the study participants (n = 136)

Sociodemographic characteristics	Anxiety (according to BAI score)			Statistical test	
	Low anxiety (%)	Moderate-to-severe anxiety (%)	Total (%)	Chi-square	P Value
Age					
≤34 years	58 (72.5)	22 (27.5)	80 (100)	0.646	0.421
>34 years	37 (66.1)	19 (33.9)	56 (100)		
Sex					
Male	10 (66.7)	5 (33.3)	15 (100)	0.081	0.771
Female	85 (70.2)	36 (29.8)	121 (100)		
Educational status					
Illiterate	9 (75.0)	3 (25.0)	12 (100)	3.804	0.283
Primary school	43 (69.4)	19 (30.6)	62 (100)		
Middle school	33 (76.7)	10 (23.3)	43 (100)		
High school and above	10 (52.6)	9 (47.4)	19 (100)		
Relationship with child					
Mother	69 (71.9)	27 (39.1)	96 (100)	5.569	0.135
Father	16 (66.7)	8 (33.3)	24 (100)		
Grandmother	5 (45.5)	6 (54.5)	11 (100)		
Grandfather	5 (100)	0 (0)	5 (100)		
Occupation					
Home maker	64 (66.7)	32 (33.3)	96 (100)	1.574	0.227
Others	31 (77.5)	9 (22.5)	40 (100)		
SES class*					
Upper class	14 (60.9)	9 (39.1)	23 (100)	4.501	0.342
Middle class	29 (65)	15 (35)	44 (100)		
Lower class	52 (75.4)	17 (24.6)	69 (100)		
Total	95 (70)	41 (30)	136 (100)		

*SES Class: By clubbing of SES classes according to modified B.G. Prasad Scale (April 2019), mentioned in methodology section

Sex, educational status, relationship with the child were found to be significantly associated with the level of depression and the association was statistically significant ($P < 0.05$) [Table 4].

DISCUSSION

It is well known fact that mothers are the main caregivers to the children. In this study also we had found that majority (70.6%) of the caregivers were the mothers of the children.

It is well-established fact that the caregivers of children suffering from Thalassemia will invariably suffer from varied degrees of anxiety and depression. This is due to long term treatment, increased out of pocket expenditure, chronicity of the disease which reduces the life span of the children. This study showed that majority (69.9%) of the study participants had mild anxiety and 30.1% moderate-to-severe anxiety. Among those who had moderate-to-severe anxiety, 29.8% were female and 33.3% were male. In a study by Yengil *et al.*^[9] found that, majority of the caregivers (63.6%) with moderate or severe anxiety symptoms were mothers, rate of anxiety was 25% among all mothers and 10.3% among all fathers. Therefore, this study results were different from the study done by Yengil *et al.*^[9]

In this study we had found that, most of the caregivers (54.4%) had moderate depression followed by 30.1% with mild mood disturbances. In a study by Shargi *et al.*^[10] reported the frequency of depression as 51%. Another study by Aziz *et al.*^[11] reported that the rate of depression as 71%. In our study, depression symptoms were detected in 28.6% of the caregivers of thalassemia patients. Both the studies had almost similar results like our studies.

This study showed that, among the caregivers with moderate depression 56.2% were female and 40% were male. So depression were more common among female caregivers compared to male caregivers. Among the caregivers with moderate-to-severe anxiety 29.8% were female and 33.3% were male. In a study by Yengil *et al.*^[9] found that the caregivers with depression symptoms, 61.1% were mothers, whereas 27.8% were fathers. Depression was present in 39.3% of all mothers, whereas in 17.2% of all fathers. Our results were close to the results found by Yengil *et al.*^[9]

In this study it was found that caregivers belonged to higher SES Class and with higher educational status were more depressed than lower SES Class and illiterate. This finding may be due to the facts that caregivers belonged to lower SES class are usually less educated than the higher

Table 4: Association of depression with sociodemographic characteristics of the study participants (n = 136)

Sociodemographic characteristics	Depression (according to BDI score)				Statistical test	
	Normal-to-mild mood disturbance (%)	Moderate depression (%)	Severe depression (%)	Total (%)	Chi-square	P Value
Age						
≤34 years	39 (48.7)	41 (51.3)	0 (0)	80 (100)	2.443	0.295
>34 years	22 (39.3)	33 (58.9)	1 (1.8)	56 (100)		
Sex						
Male	8 (53.3)	6 (40)	1 (6.7)	15 (100)	8.981	0.011
Female	53 (43.8)	68 (56.2)	0 (0)	121 (100)		
Educational status						
Illiterate	6 (50)	5 (41.6)	1 (8.4)	12 (100)	12.978	0.043
Primary school	31 (50)	31 (50)	0 (0)	62 (100)		
Middle school	18 (41.8)	25 (58.2)	0 (0)	43 (100)		
High school and above	6 (31.6)	13 (68.4)	0 (0)	19 (100)		
Relationship with child						
Mother	42 (43.8)	54 (56.2)	0 (0)	96 (100)	14.200	0.027
Father	10 (41.7)	14 (58.3)	0 (0)	24 (100)		
Grandmother	5 (45.4)	5 (45.4)	1 (9.2)	11 (100)		
Grandfather	4 (80)	1 (20)	0 (0)	5 (100)		
Occupation						
Home maker	41 (42.7)	54 (56.2)	1 (1.1)	96 (100)	0.954	0.621
Others	20 (50)	20 (50)	0 (0)	40 (100)		
SES class*						
Upper class	6 (26.1)	17 (73.9)	0 (0)	23 (100)	7.706	0.103
Middle class	18 (40.9)	25 (56.8)	1 (2.3)	44 (100)		
Lower class	37 (53.6)	32 (46.4)	0 (0)	69 (100)		
Total	61 (44.9)	74 (54.4)	1 (0.7)	136 (100)		

*SES Class: By clubbing of SES Classes according to modified B. G. Prasad Scale (April 2019), mentioned in methodology section

SES class. So they had little knowledge and less concerned about thalassemia. Caregivers belonging to higher SES class and higher educational status had better knowledge about thalassemia. They were more concern about the chronicity and fate of the disease. Therefore, they were more depressed. A study conducted by Shaligram,^[12] which shows different result from this study. They had shown lower educational status had poorer impact on psychiatric problems.

This study also revealed that there were statistically significant association between caregiver's sex, educational status, relationship with the child and the level of depression.

Limitations

The other possible factors which might be responsible for anxiety and depression of the caregivers should be properly explored. It is always better to perform a case-control study to find out the responsible factors for anxiety and depression among the caregivers of thalassemic children.

CONCLUSION

Most of caregivers were female with educational qualification of the most of them were up to primary

school. Most of the caregivers were homemakers by occupation and most of them belonged to lower middle class.

Counseling and psychotherapy for family members of the patients with thalassemia can be provided by health care personnel. The need of social support and community involvement should be emphasized to reduce stigma.

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Conflicts of interest

There are no conflicts of interest.

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