

## Burden of Care among Mothers Having Children with Thalassemia

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### ABSTRACT

#### Introduction

Thalassemia, an inherited disorder is characterized by reduction in the ability of the body to synthesize hemoglobin. Though care giving is a normal parental duty, providing lifelong care to thalassemic children may increase burden among parents. The objective of this study was to find out the burden of care among mothers having thalassemic children.

#### Methods

This descriptive cross-sectional study was carried out among 100 mothers attending a Thalassemia day care center in Kathmandu, Nepal. Non-probability purposive sampling technique was used to collect data through interview using Zarit Burden Interview scale.

#### Results

Findings revealed that out of 100 mothers, 19% had little or no burden, 43% had mild level of burden of care, 34% had moderate burden of care and 4% had severe burden of care. It was found that 43% of the mothers frequently felt that child is depended upon her, 20% of the mothers, frequently felt stressed from caring their children. 35% of the mothers frequently felt that money is insufficient to care for their child. Statistically significant association was found between level of burden with economic status ( $p=0.002$ ) and place of residence ( $p=0.03$ ).

#### Conclusion

The study concludes that mothers face burden of caring the child having thalassemia. Burden of care among mothers tends to be influenced by the family economic status and residence. This burden should be minimized by health personnel through proper counseling and support to mothers of thalassemic children.

#### Keywords

*Burden of care, mothers, thalassemia, thalassemic children*

## INTRODUCTION

Thalassemia is an inherited disorder of the blood, with deficiency of hemoglobin molecule in the red blood cells.<sup>1</sup> Thalassemia poses a serious public health problem due to its the chronicity and complications affecting the quality of life of the individuals.<sup>2</sup> In India, approximately, 10,000 children with thalassemia major are born annually.<sup>3</sup> In the context of Nepal, 4% of total populations are carrier of beta thalassemia and expected birth of newborn with beta thalassemia is 836 births per year.<sup>4</sup>

There is no definitive cure for thalassemia and blood transfusions is the only treatment option which creates a burden not only on health system but also on affected families.<sup>5</sup> The psychological burden on parent increases, due to their inability to cope with painful situations that occurred in their children's life.<sup>6</sup> The high frequency of ill-health, treatment expenses, complications, low life expectancy of the thalassemic children increase psychological burden on parents.<sup>7,8</sup>

Studies have shown the risk factors of caregiver burden as female sex, low educational status, long duration of caregiving, social isolation, financial problem and lack of choice in being a caregiver.<sup>9</sup> Often, it is the mothers who are confronted with the various stressors of taking care of their thalassemic child.<sup>10</sup> The purpose of this study was to find out the care burden among the mothers having Thalassemic children.

## METHODS

A descriptive cross sectional study design was used to find out the care burden of mothers with thalassemic children. Sample size was calculated using the Cochran formula considering the prevalence of burden of care as 60.6%<sup>8</sup> and allowable error as 5% and was adjusted to the finite population of 125 and 5% non-response rate was added. Thus total sample size was 100 mothers having thalassemic children aged within 18 years of age, who were attending the day care center of Thalassemia Society, Kathmandu Nepal. Non-probability purposive sampling technique was used to select the mothers.

Research proposal was approved by the Institutional Review Committee of Tribhuvan University, Institute of Medicine. Formal permission for data was collection was obtained from the head of the Thalassemia Society by submitting the request letter from Maharajgunj Nursing Campus, Maharajgunj. A structured interview schedule consisting of questions related to socio-demographic and disease related characteristics and Zarit Burden Interview (ZBI) was used for data collection. The ZBI scale consisted of 22 items in a five point Likerts scale with the score ranges from 0 to 88. Level of

burden was categorized as little or no burden (score between 0-20), mild burden (score between 21-40), moderate burden (score between 41 -60) and severe burden (score between 61- 88). Permission to use ZBI scale was obtained from Mapy Research Trust. Mothers were explained about the voluntary nature of participation and that they could leave the study at any time if they wished even if they participate. Written consent was taken from the mothers before including them in the study. Data were collected from 2nd to 28th September, 2018 by interviewing the mothers in a separate room in the day care centre of the Thalassemia Society. Collected data were entered in SPSS version 16 and analyzed by using descriptive statistics and inferential statistics with 0.05 level of significance

## RESULTS

More than half (56%) of the respondents were in the age group of less than 32 years, 67% of the respondents belonged to disadvantaged Janjati. More than half (54%) of the respondents resided in rural area and almost all (91%) of the respondents were able to read and write. Majority (61%) of the respondents belonged to nuclear family. Almost all (91%) of the respondents had non- consanguineous type of marriage. Nearly half (46%) of the respondents were home manager. More than half (58%) had income insufficient for one year.

Two-fifth (40%) of the children were in 7-12 years of age group. Three-fifth (60%) of the children were male. Likewise, almost all (95%) of them did not have the affected sibling and more than half (59%) of children were first born-children in the family. Cent percent of the child suffered from beta thalassemia major. Among them, majority (79%) of child started treatment from 2 years of age. Similarly, majority of children (85%) used mixed therapy for treatment of disease. In regard to treatment complication, majority of children (81%) did not have any treatment complication and only 19% had treatment complication. Among them, majority of (73.7%) of the child had splenomegaly.

Table 1 shows that nearly half of the mothers (43%) had mild burden of care while nearly two third (34%) had moderate burden of care and only 4% had severe burden of care.

Table 1. Level of burden of care among mothers

Level of burden	Percent
Little or no burden (0-20)	19
Mild burden (21-40)	43
Moderate burden (41-60)	34
Severe burden (61-88)	4

Table 2. Burden of care among mothers related to relationship and emotional wellbeing

Burden	Response				
	0	1	2	3	4#
Burden in the relationship					
Asked for more help than required	17	25	41	14	3
Felt child is dependent upon her	9	11	25	43	12
Felt lack of privacy because of child	25	30	30	12	3
Felt expectation from child to take care of him/her	20	43	23	8	6
Wished to leave the care of child to someone else	53	31	13	1	2
Felt of doing more for child	4	14	37	30	15
Emotional well being					
Had not enough time for self	26	19	39	13	3
Felt embarrassed over child's behavior	58	24	17	1	0
Felt angry when child is around	46	30	21	2	1
Felt strained when child around	40	32	15	13	0
Felt health has suffered because of caring	34	31	30	3	2
Felt you could do a better job in caring	3	12	36	14	2
Overall, felt burdened in caring	13	24	51	10	2
Social and Family life					
Felt stressed from caring	18	18	42	20	2
Caring affected relationship with others	46	40	9	3	2
Felt that social life had suffered because of caring	34	31	30	3	2
Felt uncomfortable of having friend, because of child	48	41	8	3	0
Finances					
Felt that not enough money to care of child	10	10	27	35	18
Loss of control over one's life					
Afraid what would be the future of the child	6	9	21	30	34
Felt unable to care of child much longer	38	30	21	7	4
Felt loss of control of life since child's illness	42	43	10	3	2
Felt uncertain about what to do with child	20	18	30	18	14

Table 2 shows 41% of mothers had sometimes felt about asking more help than required. Nearly half (43%) of the mothers had quite frequently felt that their child was dependent upon them. 42% of mothers had sometimes felt stressed from caring. Similarly, nearly half (46%) of mothers had never felt that caring affects relationship with others. About one third (34%) of mothers never felt that social life has suffered because of caring. Likewise, nearly half (48%) of mothers never felt uncomfortable of having friend because of child. Furthermore, one third (35%) of respondents quite frequently felt that not enough money for child care.

Table 3 shows that there is statistical association between level of burden of care and place of residence ( $p$  value 0.03). Similarly, there is strong statistical association between level of burden and economic status of respondents with ( $p$  value 0.002). But there was no statistical association between level of burden of care and age, education, type of family, occupation and duration of caregiving at 0.05 level of significance.

Table 4 shows that there is no statistical association

between level of burden and age, sex, birth order and sibling affected at 0.05 level of significance.

Table 5 shows that there is no statistical association between level of burden and duration of illness, Treatment modalities and Presence of complication at 0.05 level of significance.

## DISCUSSION

Regarding the level of burden this study showed that nearly one-fifth (19%) of the mothers had no burden, nearly half (43%) of the mothers had mild burden of care while about one-thirds (34%) had moderate burden of care and very few (4%) had severe burden of care. These findings are supported by the findings of the study done in India by Khanna et al.<sup>11</sup> which showed that 25% of mothers had no burden of care, 37% had mild burden of care. These study findings are somewhat similar with the findings of another study done in India by Inhdar<sup>8</sup> among 35 parents which showed that 40% of the mothers had little or no burden of care, 37.4% had mild burden of care, 20.6% had moderate burden and 2.86% felt severe burden of care. These study

Table 3. Association of level of burden of care with selected demographic variables of mothers

Characteristics	Level of Burden			Chi square value	p value
	Little or No Burden No. (%)	Mild Burden No. (%)	Moderate to Severe Burden No. (%)		
Age					
Up to 31 years	8 (14.8)	23 (42.6)	23 (42.6)	1.7	0.42
Above 31 years	11 (23.9)	20 (43.5)	15 (32.6)		
Place of Residence					
Rural	9 (16.7)	18 (33.3)	27 (50)	7.3	0.03*
Urban	10 (21.7)	25 (54.3)	11 (23.9)		
Education Level					
Up to secondary	12 (16.4)	31 (42.5)	30 (41.1)	1.6	0.44
Above secondary	7 (25.9)	12 (44.4)	8 (29.6)		
Type of Family					
Nuclear	8 (13.1)	30 (49.2)	23 (37.7)	4.2	0.12
Joint	11 (28.2)	13 (33.3)	15 (38.5)		
Occupation					
Home maker	8 (17.4)	20 (43.5)	18 (39.1)	0.1	0.93
Working outside home	11 (20.4)	23 (42.6)	20 (37)		
Economic status					
Poor economic status	12 (20.7)	26 (44.8)	20 (34.5)	17.2#	0.002**
Middle economic status	3 (11.5)	6 (23.1)	17 (65.4)		
High economic status	4 (25.0)	11 (68.8)	1 (6.3)		
Duration of Care giving					
Up-to 6 Years	11 (22.0)	18 (36.0)	21 (42.0)	2	0.36
Above 6 Years	8 (16.0)	25 (50.0)	17 (34.0)		

Table 4. Association of level of burden of care with selected child-related variables

Characteristics	Level of Burden			Chi square value	p value
	Little or No Burden No. (%)	Mild Burden No. (%)	Moderate to Severe Burden No. (%)		
Age					0.15
Up to 8 years	10 (21.7)	15 (32.6)	21 (45.7)	3.7	
Above 8 years	9 (16.7)	28 (51.9)	17 (31.5)		
Sex					0.38
Male	11 (18.3)	23 (38.3)	26 (43.3)	1.9	
Female	8 (20.0)	20 (50.0)	12 (30.0)		
Birth order					0.50
1st	9 (15.3)	26 (44.1)	24 (40.7)	1.3	
2nd and above	10 (24.4)	17 (41.5)	14 (34.1)		
Sibling affected					0.50#
Yes	1 (20.0)	1 (20.0)	3 (60.0)	1.3#	
No	18 (18.9)	42 (44.2)	35 (36.8)		

findings are in contrast with the findings of the study done in Mexico by Pineda et al. 2016<sup>12</sup>, among 110 caregivers which showed that 30% of the respondents had severe burden. This difference might be due to difference in setting and sample size.

Likewise, in this study highest burden was seen in finance domain and lowest burden was seen in social and family life domain. This finding is contradictory with the finding of the study done in Bangalore by Shanmugam et al,<sup>3</sup> which showed that lowest burden was found in finances domain.

Table 5. Association of level of burden with selected disease and treatment related variables

Characteristics	Level of Burden			Chi square value	p value
	Little or No Burden No. (%)	Mild Burden No. (%)	Moderate to Severe Burden No. (%)		
Duration of Illness					
6 Month to 6 Years	11 (22.0)	18 (36.0)	21 (42.0)	4.0#	0.40#
7-12 years	5 (14.3)	16 (45.7)	14 (40.0)		
Above 12 years	3 (20.0)	9 (60.0)	3 (20.0)		
Treatment modalities					
Blood Transfusion	5 (33.3)	6 (40.0)	4 (26.7)	2.3#	0.32#
Mixed Therapy	14 (16.5)	37 (43.5)	34 (40.0)		
Complications					
Present	1 (5.3)	8 (42.1)	10 (52.6)	4.2#	0.12#
Absent	18 (22.2)	35 (43.2)	28 (34.6)		

This study showed statistical association between level of burden and economic status ( $p=0.002$ ). This finding is supported by the study done in Iran by Piran,<sup>13</sup> where there was significant relationship between burden and economic status ( $p=0.03$ ).

The findings of this study showed a statistically significant association between level of burden and place of residence ( $p=0.03$ ). This finding is supported by the finding of study done in Iraq by Aziz et al,<sup>14</sup> which showed that there was significant association between residential area of caregivers with social burden ( $p=0.006$ ). A similar finding was reported by another study done in Pakistan by Zaheer et al<sup>15</sup> which showed significant association between psychological burden and place of residence ( $p=0.02$ ).

The findings of this study showed no statistical association between the level of burden and occupation ( $p=0.83$ ). In contrast to this, a study done in Iraq, by Aziz et al,<sup>14</sup> reported that there was significant association between psychological burden and occupation of parents ( $p<0.001$ ) and with social burden of parents at ( $p<0.001$ ). The difference in findings of two studies may be due to difference in socioeconomic status of the two societies.

This study showed that there was no statistical association between the level of burden and age of the respondents ( $p=0.31$ ). This finding is supported by a study carried out by Aziz et al<sup>16</sup> in Pakistan, which showed that the age of the parents had no significant association with psychological burden. Similar finding was reported by another study, conducted in Iran by Mashayekhi et al<sup>17</sup> which also found no significant association between the mother's age and burden of care ( $p$  value= $-0.049$ ).

This study found no statistical association between level of burden and type of family ( $p=0.94$ ). This

finding is supported by a study carried out by Zaheer et al<sup>15</sup> which also found no significant association between psychological burden and type of family ( $p=0.06$ ). This study showed that there was no statistical association between level of burden and age of children ( $p=0.15$ ). This finding is inconsistent with the study done by in Bangalore by Saldanha<sup>18</sup> which showed that there was a significant relationship between burden and children's age ( $p=0.048$ ).

The study found no statistical association between level of burden and duration of illness ( $p=0.40$ ). This finding is inconsistent with the study done in Bangalore by Saldanha<sup>18</sup>, which showed that there was significant relationship between burden and duration of illness revealing that with increased duration of illness, the burden of care also increased ( $p = 0.048$ ).

## CONCLUSION

On the basis of the study findings, it is concluded that mothers having children with thalassemia have burden of care. Burden of care tends to be influenced by economic status and place of residence. So, concerned authority should plan and conduct different program to support those mothers having thalassemic children so as to reduce the burden of care among the mothers.

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## CONFLICT OF INTEREST

The author(s) declare that they do not have any conflicts of interest with respect to the research, authorship, and/or publication of this article.

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