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Psychological Burden Faced by Parents having Children with Thalassemia in a Teaching Hospital

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ABSTRACT

Introduction

Caring for a child suffering from thalassemia is very stressful for parents. The study was aimed to identify the psychological burden of parents having children with thalassemia.

Methods

Cross-sectional analytical study was done. The parents having children diagnosed with thalassemia and receiving service from Pediatric OPD, National Medical College were the study participants. Non-probability convenience sampling technique was used and sample size was 88. Data was collected through face-to-face interviews using a structured interview schedule. Data analysis was done in SPSS version 16. Chi-square test, fisher's exact test and odds ratio were used to examine the association.

Results

Mean psychological burden score was 47.47 ± 10.9, and 71.6% of parents had moderate level of psychological burden. Level of psychological burden was associated with parents' sex (p=0.03), education level (p=0.03), and income (p=0.01). Odds ratio determined that psychological burden was 2.9 times higher (95% CI = 1.1-7.6) among mothers, 3.7 times higher (95% CI = 1.4-9.9) for the parents whose income was insufficient to get their needs met. Non-literate parents were 3.6 times and parents with primary to secondary level education were 1.6 times more likely to have psychological burden. In contrast, those with higher secondary or above levels of education were less likely to perceive psychological burden (OR = 0.3, 95% CI = 0.4-1.0).

Conclusion

More than two-thirds of the parents having children with thalassemia tend to have moderate levels of psychological burden. The measures to reduce psychological burden of parents should focus more towards mothers, those parents with low education level and with less income.

Keywords

Children; parents; psychological burden; thalassemia

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INTRODUCTION

Thalassemia is an inherited blood disorder.[1,2] Alpha and beta thalassemia are most common[3] and both have mild-severe forms causing a remarkable impact on a patient's life.[4,5] Regular blood- transfusion is needed to maintain adequate haemoglobin and sustain life, while multiple transfusions cause organs to become overloaded needing iron chelation therapy.[1,4,6] Successful bone-marrow transplants, and recently, gene therapy has been successfully applied, however, it is expensive and not readily available in most settings.[1,4,6]

Thalassemia challenges family at physical, emotional, and cognitive levels and disrupts their quality of life.[7] Each year, 50,000 to 100,000 children die of thalassemia major in low-and-middle-income countries.[8] Studies from America, Iran and Pakistan reported 2 to 6% are affected and the carrier ranges from 1-13%.[9-11] In India, 6000-8000 children with thalassemia are estimated to be born every year.[12] In Nepal, 4% of the total population are a carrier of beta-thalassemia and the expected birth of children with beta-thalassemia is 836 per year.[13] A record review of Tribhuvan University Teaching Hospital shows beta thalassemia is more prevalent in the Tharu community.[14]

High frequency of treatment procedures, low life expectancy, future complications and deteriorating health of child increase psychological pressure on parents.[15-19] However, less work has been done on the stress level of parents who are caring for their children having thalassemia in Nepal. This study aimed to assess the level of psychological burden among parents having children with thalassemia. It would enable health care providers to support and reduce psychological burden of parents.

METHODS

A cross-sectional analytical study design was used. The study was conducted at Pediatric OPD, National Medical College (NMC). Parents (either father or mother) who were caring for their child (aged 1 to 19 years) diagnosed with thalassemia, and receiving service from NMC were the study population. A non-probability convenience sampling technique was used to select the sample. The total sample size was 88.

A structured interview schedule was used, which included socio-demographic information and the "Zarit Burden Interview (ZBI)" scale. ZBI is available in the public domain. It was originally developed by Steven H. Zarit in 1986 to assess the burden on caregivers of adult dementia patients. It is a widely used tool, which has been translated into number of languages. There are 22 questions on the scale with a minimum score of zero and maximum score of four in each question and the total score is 88. The level of burden obtained through ZBI scale was interpreted as: 0 - 21 Little or No burden; 21- 40 Mild burden; 41- 60 Moderate; and 61- 88 Severe burden.[20] The ZBI was translated into the Nepali language after consultation with bilingual experts. Data was collected through face-to-face interviews by the researcher and it took 25-30 minutes to collect complete data from each respondent.

Data was analyzed in SPSS version 16. Descriptive statistics (frequency, percentage, mean, median and standard deviation) were used to explain the characteristics of different variables measured in study. Chi-square and fisher's exact tests were used to identify the association between background variables and level of burden among parents. Level of significance was reported at <0.05. Odds ratio was calculated as well.

Ethical approval was obtained from the Institutional Review Committee of National Medical College (Ref. F-NMC/665/080-081). Official permission was obtained from the NMC to collect data. Written consent of parents was obtained to participate voluntarily in the study. Privacy was maintained by conducting separate interviews at Pediatric OPD, NMC.

RESULTS

Majority of parents were young adults (ages between 20 – 40 years; 70.5%) with mean age of 36.32 ± 7.8 years (Table 1). Among parents, 54.5% were mothers, and 63.6% belonged to Janajati, Madhesi, and Dalit. Regarding education status, 52.3% had up to secondary levels of education, 28.4% had agriculture as an occupation and 65.9% had income insufficient to meet their livelihood needs.

Among the parents, 8% married to first and 11.3% married to second cousins, whereas, 34.1% had a family history of thalassemia. Majority (54.5%) of the children with thalassemia were aged above 10 years with a mean age of 10.3 ± 4.5 years. Here, male (62.5%) children outnumbered female (37.5%) children. Majority (46.6%) of the children were diagnosed as having Beta Thalassemia Major.

The level of psychosocial burden of parents having children with thalassemia was calculated, moderate level of psychosocial burden was highly prevalent in 71.6 % of the parents with a mean score of 47.47 ± 10.9 (Table 2).

There was a significant association of parents' psychosocial burden with parents' sex (p=0.03), their education (p=0.03) and their income (p=0.01). Further, the odds ratio predicted that psychosocial burden was 2.9 times higher (95% CI=1.1-7.6) among mothers and 3.7 times higher (95% CI=1.4-9.9) for the parents whose income was insufficient to get their needs met. (Table 3).

***Table 1**. Socio-bio-demographic information of parents and their children (n=88)*

Characteristics		**Number (%)**
Sociodemographic characteristics of parents		
Age (in years)	20 – 40	62 (70.5)
	41 – 55	26 (29.5)
	Mean (SD): 36.32 (±7.8) years; Min.-Max.: 35-55 (years)	
Sex	Male	40 (45.5)
	Female	48 (54.5)
Ethnicity	Brahmin/Chhetri (Hill +Madhesh)	32 (36.4)
	Janajati+Dalit+Madhesi	56 (63.6)
Education	Illiterate	17 (19.3)
	Primary to secondary level	46 (52.3)
	Higher-secondary or above	25 (28.4)
Occupation	Agriculture	25 (28.4)
	Business	12 (13.6)
	Services	14 (15.9)
	Homemakers	14 (15.9)
	Labours	23 (26.1)
Income	Insufficient to meet the needs	58 (65.9)
	Sufficient to meet the needs	30 (34.1)
Married to	First cousin	7 (8.0)
	Second cousin	10 (11.3)
	Out of family	71(80.7)
Thalassemia in family	Yes	30 (34.1)
	No	58 (65.9)
Bio-demographic characteristics of children		
Age (years)	≤ 10	40 (45.5)
	>10	48 (54.5)
	Mean (SD): 10.3 (± 4.5) years; Min.-Max.: 1 – 19 years	
Sex	Male	55 (62.5)
	Female	33 (37.5)
Type of Thalassemia	Beta Thalassemia	39 (44.3)
	Beta Thalassemia Major	41 (46.6)
	Beta Thalassemia Intermediate	8 (9.1)

Abbreviation: ≤ less than and equal to; > greater than; SD = standard deviation

***Table 2.** Level of the psychosocial burden of parents*

Level of Psychosocial Burden	**Frequency (%)**
Negligible (0-20 score)	2 (2.3%)
Mild (21-40 score)	16 (18.2%)
Moderate (41-60 score)	63 (71.6%)
Severe (61-88 score)	7 (8%)
Total	88 (100%)

***Table 3**. Association between parent's bio-demographic variables and psychological burden (n=88)*

Characteristics		Negligible to mild burden No (%)	Moderate to severe burden No (%)	P-value	Odds ratio (95% CI)
Age (in years)	20 – 40	16 (25.8)	46(74.2)	0.45	
	41 – 55	9(34.6)	17 (65.4)		
Sex	Male	16(40)	24 (60)	0.03*	2.9 (1.1 – 7.6)
	Female	9 (18.7)	39 (81.3)		
Education level	Illiterate	2(11.7)	15 (90.9)	0.03**	3.6(0.7– 17.1)
	Primary to secondary	11 (23.9)	35 (75.0)		1.6 (0.6 – 4.0)
	Higher-secondary	12 (48.0)	13 (52.0)		0.3 (0.4 – 1.0)
Income to get the needs met	Insufficient	11 (18.9)	47 (81.1)	0.01*	3.7 (1.4 – 9.9)
	Sufficient	14 (46.6)	16 (53.4)		
Married to	First cousin	13 (31.7)	28 (68.3)	0.68	-
	Second cousin	10 (28.6)	25 (71.4)		
	Out of family	19(26.8)	52 (73.2)		
Thalassemia in family	Yes	5(16.6)	25 (83.4)	0.09	-
	No	20(34.5)	38(65.5)		

*Negligible to mild psychological burden = score of 0 – 40, moderate to severe psychological burden = score of 41 – 88; *significant Chi-Square test, **Fisher's exact test*

DISCUSSION

The mean age of the parents was 36.32 (±7.8) years; ranging from 20 to 55 years, 54.5 % of the participants were mothers of children. Mean age of children affected with thalassemia was 10.3 (SD 4.5) years and 62.5% were male. The finding is similar to the findings obtained from other studies on thalassemia where mean age of children was found to be within 11 to 15 years and s majority of children were male.[7, 21] Beta Thalassemia Major was reported among 46.6% of children. In educational status, the present study found that only 19.3% of the parents could not read and write (non-literate). Present study found that 80.7% of parents were married out of family relation followed by 11.3% to second cousins and 8% to first cousins. In contrast to this, a study in Pakistan revealed that out of 500 caregivers, 61.2% were married to their first cousins, 18.2% were married to their second cousins, 6.8% were married in distance relatives and 13.8% were married out of family.[22] This difference in findings may be due to differences in social, religious and cultural values in the two countries. In regard to economic sufficiency, 65.9% of the parent's income is insufficient for one year. Nearly similar finding was reported in a study by Mashayekhi et al. (2016) where 88.8% caregiver's level of income was poor.[23] Similar finding was obtained in other studies which reported that the disease has affected caregiver's financial state badly, majority of the affected children's families were poor and unable to afford the costly treatment.[22] Likewise, past studies in India and Pakistan reported that parents having children with thalassemia had severe financial stress (74% and 56% respectively).[7,11] Similarly, a qualitative study in Turkey also explored intense psychological distress, need of social support and financial burden among parents having children with thalassemia.[24] Current study found that 34.1% had history of thalassemia in family whereas from study by Saldanha (2015) reported that only 6% of the respondents had similar problems within family relations.[7]

Regarding the main aspect of this study, the psychological burden of parents assessed through Zarit burden interview, 71.6% of parents expressed moderate burden and the overall mean burden score was found to be 47.47±10.9. Qualitative studies in Turkey and Iran also explored the psychological distress a prevalent problem among parents to have children with thalassemia major. The studies have identified the psychological distress along with burnout and need of support and empathy for parents.[24, 25] But the present finding is much higher than a study by Inamdar et al. (2015) in which 37.4% parents had mild to moderate burden.[17] On the other, present study found 8% parents had high level of burden but study from Iran identified the mean parental/caregiver burden was 16.43±7.76 and 45.8% of parents had high level of caregiver burden.[26] This difference in findings may be attributed to difference in sample size as well socio-economic values and status in these different settings.

The inferential analysis revealed that age of the parents was not statistically significant which is supported by a study carried out in Pakistan, which showed that age of parents had no significant association with psychological burden.[11] However the finding is contradictory from the findings from other studies.[27,28] This dissimilar finding may be attributed to differences in sample size and settings. There was statistically significant association between parent's sex and psychological burden (p=0.034) in this study. However, finding from other studies reported no significant relation between depression and the gender of caregivers.[11,17]

Further, the psychological burden on the basis of educational status of parents was found statistically significant (p=0.024) in this study. Odds ratio revealed that illiterate parents were 3.6 times and parents with primary to secondary level education completed were 1.6 time more likely to have psychological burden, while those with higher secondary or above level of education were less likely to perceive psychological burden (OR=0.3). Previous studies in different countries also showed that education level of caregivers was significantly associated with the burden of parents.[11,17,26] However, Inamdar et al. (2015) reported the level of education does not affect the burden of parents.[17] Although most of the past studies supported present findings, some contradictory ones might be due to difference in setting.

This study also found the psychological burden was associated with income of parents (p=0.012). Psychological burden was 3.7 times higher for the parents whose income was insufficient to get the needs met. This finding is supported by past studies which reported significant association between income and the stress and burden among caregivers, that is the parents having less income experienced more stress.[7,22,29] Therefore, the parents with low economic status are at more risk of psychological burden. The nurses and health care team can concern these factors and offer support to reduce the level of psychological burden.

CONCLUSION

A significant proportion of parents having children with thalassemia have moderate to severe level of psychological burden. Those with less income, the mothers compared to fathers, and the education level below secondary or non-literate parents are found to have a higher risk of psychological burden. Therefore, the mothers, those with less education and income should be considered more in preventing from psychological burden caused by their children's thalassemia condition. The findings can assist health professionals and social workers in understanding the substantial stress, fatigue, and strain experienced by parents managing thalassemia diagnosis in their children, thereby potentially enhancing care strategies, including counselling. Additionally, further research involving larger sample sizes across diverse healthcare settings and assessing the socio-economic impacts on parents could offer a more comprehensive view of the challenges they encounter. Moreover, additional studies could investigate why parents with lower income and educational levels, as well as mothers than fathers, experience a greater psychosocial burden while caring for children with thalassemia.

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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.

AUTHOR CONTRIBUTIONS

Romina Shrestha: Research concept, research design, literature review, statistical data analysis and manuscript preparation; Rubi Shah and Keshav Bhandari: Literature review, data collection, data analysis and manuscript preparation; Ratna Shila Banstola; Literature review, statistical data analysis and manuscript preparation.

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