

Economic Evaluation of the Parents of Malnourished Thalassemia Major Patients

Muhammad Umair, Mawra Hyder, Amna Khalid, Asma Abdul Qadeer, Rafiq Ahmed Shahid,
 Rabia Mahmood, Mudassar Mushtaq Jawad Abbasi

¹Deputy Director, Provincial Health Directorate, Quetta

²Demonstrator Dept of Community Dentistry School of Dentistry/SZABMU Islamabad

³PGR Children Hospital, Pakistan Institute of Medical Sciences, Islamabad

⁴Associate Professor Dept of Community Medicine Rawal Institute of Health Sciences, Islamabad

⁵Associate Professor Dept of Pathology, Sharif Medical & Dental College, Lahore

⁶Assistant Professor Dept of Community Medicine Federal Medical College Islamabad

⁷Assistant Professor Health Services Academy, Islamabad

Author's Contribution

¹Provided concept/research design, ¹data collection, responsibility and is accountable
^{5,6}Edit of manuscript, critical revision of the manuscript for important intellectual content
⁷statistical analysis and
^{3,4}manuscript writing

Funding Source: None

Conflict of Interest: None

Received: Jan 19, 2024

Accepted: May 21, 2024

Address of Correspondent

Dr Muhammad Umair
 Deputy Director, Provincial Health Directorate, Quetta
 drumair8677@gmail.com

ABSTRACT

Objective: To evaluate economic status of the parents of malnourished thalassemia major patients admitted in hospitals of Quetta

Methodology: This cross-sectional study was conducted at Bolan Medical Hospital (BMCH), and Sandeman Provincial Hospital (SPH), Quetta from July to Sept 2020. A sample size of 100 was calculated by using the sample size calculation formula. Parents of malnourished patients, admitted in the pediatric wards were included while rest of the parents with the problems other than the malnutrition were excluded. Data were collected by preformed structured questionnaire via systematic random sampling. Ethical consideration was taken from Institutional Review Board (IRB) of Health Services Academy (has) and the participants prior to the study. Data were analyzed by using the SPSS version 20. 2 Chi square test was applied, P-value < 0.05 was taken as significant

Results: Among 100 respondents, 65 were males and 35 were females. About half (47%) subjects were accompanied with father. 75% of the respondents having 1 to 11 family members, while 64% of the thalassemia major patients told that their parents were cousins. All participants reported no assets like their own home, car, bank balance, and even the animals. About 61% of the parents of thalassemia major had their monthly income in between 10,000 rupees to 15,000 rupees. There was insignificant relationship between gender, average income per month with level of satisfaction (p-value 0.086, 0.298) respectively.

Conclusion: All the participants said that government should launch a nationwide program for inexpensive treatment of thalassemia major. All of the parents had no assets and their monthly income was very low, so they have to spent their money to come to hospital.

Keywords: Economic evaluation, malnutrition, parents, thalassemia major.

Cite this article as: Umair M, Hyder M, Khalid A, Qadeer AA, Shahid RA, Mahmood R, et al. Economic Evaluation of the Parents of Malnourished Thalassemia Major Patients. *Ann Pak Inst Med Sci.* 2024; 20(3):227-231. doi. 10.48036/apims.v20i3.1000.

Introduction

Acceptable nutrition, start in early stages of life, is critical to ensure upright physical and mental progress and long-term health. Malnutrition or malnourishment is a condition that results from eating a diet in which nutrients are either not enough or are too much such that the diet causes health

harms.¹ Malnutrition is common. Thalassemia is autosomal recessive single-gene disorder because of imbalance in production of α -globin and β -globin chains, having an impact on the nutritional status. Malnutrition is among one of effects of a thalassemia due to fast erythrocyte turnover. According to global data, 7% populace is carrier of thalassemia traits. About 300,000 to

500,000 babies yearly are born with the hemoglobinopathies.² Asian countries suffer from high prevalence malnutrition.³ Severe childhood malnutrition harms development and growth.⁴ Furthermore, undernutrition causes raise of healthcare costs, and contraction of economic development.⁵

Undernourishment is most frequently due to not enough good food being available to eat. Additional reasons of malnutrition comprise anorexia nervosa and bariatric surgery. Energies to improve nutrition are some of the greatest effective forms of development aid.¹

Closely 1 billion people were undernourished; 1 billion of them were previously overweight and obese and nearly 2 billion were misery from hidden starvation globally. Systematic review and meta-analysis of literature confirmed the nutritional issues of under-five children. Factors like food insecurity coping strategies, the health status of children, maternal health, political systems the country, and communities cultural background were major determinants of under-five children malnutrition.⁶ 3.1 million children died because of malnutrition in 2020.⁷

Study in Bangladesh showed that the Malnutrition is one of the important public health concerns in developing countries and the leading cause of child mortality. Malnutritional problem is multi-dimensional, having connections to social, economic and demographic conditions.⁸

Good sanitation also plays a major role. Children residing in the region, where hygiene conditions are bad are at high risk of developing malnutrition.⁹

Immune system of the malnourished children gets very weak that can lead to the attack of the severe infections and vaccines play major role in preventing the child from different diseases. If the children get vaccinated then there will be less odds of the children to get sick and end up as malnourished.¹⁰

Study has shown that malnutrition upsurges Hospital admissions, hospital stay, as well as hospital readmission following discharge from hospital. Public spending on malnutrition was estimated to be £19.6 billion in England in 2011–12, or additional than 15% of the total spending on health and social care.¹¹⁻¹³ Undernutrition is often associated with poverty and high food prices.¹⁴

Objective of this study was to evaluate economic status of the parents of malnourished thalassemia major patients admitted in hospitals of Quetta.

Methodology

This cross sectional study was conducted at Bolan Medical Hospital (BMCH), and Sandeman Provincial Hospital (SPH), Quetta from July to Sept 2020. Sample size of 100 was calculated using the WHO calculator. 10% additional sample was included to overcome loss of data.

Participants who do not have any other systemic disease, don't have hearing or talking issues, without any mental confusion were included in this study. Rest of the parents with the problems other than the malnutrition were excluded. Data was collected by preformed structured questionnaire via systematic random sampling. 5-item Likert-type satisfaction scale was used. Responses were scored as follows: (1) strongly disagree, (2) agree a little, (3) agree moderately, (4) strongly agree, and (5) agree completely. The higher the score, the higher the respondent's level satisfaction.¹⁵ Questionnaire was divided in different portions that include the quantitative portion having demographic information of the patient and the parents, then the economic burden of the family by asking the different questions regarding the disease expenditure, parents earning and occupations. Ethical Consideration was taken from IRB of HSA and the participants prior to the study. Data was analyzed by using the SPSS version 20. 2. Chi square test was applied, P-value < 0.05 was taken as significant.

Results

Among the respondents more than half (65) out of 100 were males and 35 of them were females. Regarding the age groups of the respondents about 35 were about 2 to 4 years of age group, about 48 were from 5 to 7 years of age. About half (47%) were accompanied with father, about quarter (25%) were accompanied with mother and 28% of them were accompanied with both parents. 75% of the respondents having 1 to 11 family members at their home and 18% of them having 11 to 20 family members at their home. 64% of the thalassemia major patients told that their parents were cousins and 36% of the parents have non consanguineous marriage. (Table I)

The economic evaluation of the parents of the thalassemia major parents and found that about 100% having no assets like their own home, car, bank balance, and even the animals. About 61% of the parents of thalassemia major had their monthly income in between 10000 rupees to 15000 rupees and about 25% of the parents of the thalassemia major children having 15000 to 20000 rupees per month income. Seventy-two percent participants came

from urban area, while 28% belonged to rural area. As shown by table II.

Table I: Demographic characteristics of study population.		
Demographic characteristic	N	%
Age groups:		
2–4 years	35	35%
4–7 years	48	48%
7–10 years	9	9%
10–14 years	8	8%
Patient accompanied with:		
Father	47	47%
Mother	25	25%
Both	28	28%
Number of family members		
1–10	75	75
11–20	18	18
21–30	7	7
Cousin marriage:		
Yes	64	64
No	36	36

Table II: Economic evaluation of the parents of thalassemia major patients.		
Economic evaluation	N	%
Assets if the family		
No assets (no home, no vehicle)	100	100
Average income per month		
10000Rs to 15000Rs	61	61
15001Rs to 20000Rs	25	25
20001Rs to 25000Rs	2	2
25001Rs to 30000Rs	12	12
Area came from		
Urban	72	72
Rural	28	28

Table III: Association between different variables with level of satisfaction.			
Variables	Satisfied %	Dissatisfied %	P value
Gender			
Male	52.3	47.7	0.086
female	68.6	31.4	
Patient accompanied with			
Father	59.6	40.4	0.855
Mother	60	40	
Both	58	42	
Average income per month			
10000-15000rp	60.7	39.3	0.298
15001-20000rp	52	48	
20001-25000rp	0	100	
25001-30000rp	67.7	32.3	

There was insignificant relationship between gender and level of satisfaction (p-value 0.086). Similarly, an insignificant relationship was also seen between average income per month and level of satisfaction (p-value 0.298). As shown by table III.

Discussion

When talking about Asia, according to 2021 report, 1000 thalassemia patients were there in two cities of Indonesia.¹⁶ An Indian study found that 328 thalassemic patients were malnourished.¹⁷ Primary-care physicians play an important role in maintenance of general health of these patients.¹⁸ There is reduced nutrients intake and hypoxia of gut resulting in poor appetite and malabsorption.¹⁹ An individual's capacity to access the healthcare is interceded by socioeconomic status.²⁰⁻²²

In this study, almost half of participants were between 4–7 years age, which is different from another study where merely 1.1% subjects were 4years of age. Twenty-five percent children were accompanied by mothers, which is one-third of the percentage reported by another author.²³

Thalassemia is common in this region, as the results showed the male are more effected than the females in this blood related disorder, which means that males are prone to have this disorder because females required two effected genes and the males needs only one effected gene, there was a difference the per month visits for the transfusions because the parents who used to come for the transfusion for 1 or 2 times per month they have to come for 3 or even 4 times because of non-availability of the blood whereas research conducted in Lahore Sir Ganga ram hospital showed that there mostly the respondents came once or twice for the transfusion but here the non-availability of the blood made the respondents visits more often, findings were not matching because of the non-availability of certain blood groups here.²⁴

Cousin marriages were among 64% parents, which is comparable to percentages of other investigations where 72% & 78.5% partakers were cousins.^{25,26}

The patients fear the financial problems because they are mostly worked on daily bases and parents need to be educated about the disease and also about the premarital screening their level of stress depends on their employment levels as well, findings of the study showed that the circumstances in Iran and in our country is same a similar study conducted in Iran published showed employment status play very important role in stress levels.²⁷

More than 80% of parents reported that they had their monthly income in between 10000 rupees to 20000 rupees, which is comparable to other studies where majority of fathers reported monthly income of 10000-20000 Rs.²⁸

In this study, an insignificant relationship was seen between average income per month and level of satisfaction (p-value 0.298). This is synchronized with the findings of another study.²⁹ Similarly, there was insignificant relationship between gender and level of satisfaction (p-values 0.086), which is same as that of Bangladeshi study.²⁹

Conclusion

All of the parents have no assets and their monthly income was very low, so they have to spent their money to come to hospital. All the patients said that government should launch a nation-wide program for inexpensive treatment of thalassemia major.

References

- Hoseini BL, Moghadam ZE, Saeidi M, Rezaei M. Child Malnutrition at Different World Regions in (1990-2013). 2013;3(21):921-32.
- Ayukarningsih Y, Amalia J, Nurfarhah G. Thalassemia and nutritional status in children. *J Health & Dental Sciences*. 2022 Jun 9;2(1):39-52. <https://doi.org/10.54052/jhds.v2n1.p39-52>
- Li X, Yadav R, Siddique KH. Neglected and underutilized crop species: the key to improving dietary diversity and fighting hunger and malnutrition in Asia and the Pacific. *Front Nutr*. 2020 Nov 19;7: 593711. <https://doi.org/10.3389/fnut.2020.593711>
- Kirolos A, Goyheneix M, Elias MK, Chisala M, Lissauer S, Gladstone M et al. Neurodevelopmental, cognitive, behavioural and mental health impairments following childhood malnutrition: a systematic review. *BMJ global health*. 2022 Jul 1;7(7): e009330. <https://doi.org/10.1136/bmigh-2022-009330>
- World Health Organization. Global Database on Child Growth and Malnutrition. Available online: <http://www.who.int/nutgrowthdb/estimates/en/> (accessed on 28 Jan 2021)
- Tebeje NB, Bikes GA, Abebe SM, Yesuf ME. Prevalence and major contributors of child malnutrition in developing countries: systematic review and meta-analysis. *J Child Obes*. 2017;2(4): 1-7. <https://doi.org/10.21767/2572-5394.100037>
- World Health Organization. UNICEF/WHO/The World Bank Group joint child malnutrition estimates: key findings of the 2021 edition. Available from: [https://www.who.int/data/gho/data/themes/topics/joint-child-malnutrition-estimates-unicef-who-wb#:~:text=In%202020%2C%20149.2%20million%20children,for%20their%20height%20\(overweight\)](https://www.who.int/data/gho/data/themes/topics/joint-child-malnutrition-estimates-unicef-who-wb#:~:text=In%202020%2C%20149.2%20million%20children,for%20their%20height%20(overweight).). Accessed June 1, 2023.
- Rahman A, Hakim MA. Malnutrition prevalence and health practices of homeless children: A cross-sectional study in Bangladesh. *Science Journal of Public Health*. 2016;4(1):10-5.
- Gilmartin AA, Petri Jr WA. Exploring the role of environmental enteropathy in malnutrition, infant development and oral vaccine response. *Philosophical Transactions of the Royal Society B: Biological Sciences*. 2015 Jun 19;370(1671):1-7. <https://doi.org/10.1098/rstb.2014.0143>
- Prendergast AJ. Malnutrition and vaccination in developing countries. *Philosophical Transactions of the Royal Society B: Biological Sciences*. 2015 Jun 19;370(1671):1-8 <https://doi.org/10.1098/rstb.2014.0141>
- Carvalho-Salemi J, Salemi JL, Wong-Vega MR, Spooner KK, Juarez MD, Beer SS. Malnutrition among hospitalized children in the United States: changing prevalence, clinical correlates, and practice patterns between 2002 and 2011. *Journal of the Academy of Nutrition and Dietetics*. 2018 ;118(1):40-51. <https://doi.org/10.1016/j.jand.2017.02.015>
- Elia M. The cost of malnutrition in England and potential cost savings from nutritional interventions (short version). Malnutrition Action Group of BAPEN and the National Institute for Health Research Southampton Biomedical Research Centre: Southampton, UK. 2015 May:1-22
- Meher BK, Panda I, Mishra NR, Das L, Sahu B, Meher BK, MISHRA NR. The impact of COVID-19 on pediatric healthcare utilization and disease dynamics: An observational study from Western Odisha. *Cureus*. 2022 ;14(7):1-11. <https://doi.org/10.7759/cureus.27006>
- Maternal, newborn, child and adolescent health. WHO. Available at: http://www.who.int/maternal_child_adolescent/en/. Accessed on 4 Jan 2024
- Seviç S. Life satisfaction and difficulties experienced by the family members of individuals with thalassemia. *Nursing Open*. 2023. <https://doi.org/10.1002/nop2.1649>
- Alwi, Z. B., & Syed-Hassan, S. N. R. K. (2022). Thalassemia in Malaysia. *Hemoglobin*, 46(1), 45–52. <https://doi.org/10.1080/03630269.2022.2057326>
- Biswas B, Naskar NN, Basu K, Dasgupta A, Basu R, Paul B. Malnutrition, its attributes, and impact on quality of life: an epidemiological study among β -Thalassemia major children. *Korean J Fam Med* 2021; 42 (1): 66-72. <https://doi.org/10.4082/kjfm.19.0066>
- Raghuwanshi B, Kumari S, Sahoo DP. Clinical and Metabolic Complications in patients with thalassemia undergoing transfusion therapy. *J Family Med Prim Care*. 2020; 9(2):973-77 https://doi.org/10.4103/jfmpc.jfmpc_845_19
- Soliman A, Yassin M, Alyafei F, Alaaraj N, Hamed N, Osman S, Soliman N. Nutritional studies in patients with β -thalassemia major: A short review. *Acta Bio Medica: Atenei Parmensis*. 2023;94(3). [doi: 10.23750/abm.v94i3.14732](https://doi.org/10.23750/abm.v94i3.14732)
- Javaid MM, Tariq MA, Sajid M, Uraneb S, Zia Q, Umer MF et al. Impact of Socioeconomic Status and Duration of HIV/AIDS on Scarcity of Vitamin-D among HIV Infected Patients. *Pak J Public Health*. 2023 Jun 30;13(2):84-7. <https://doi.org/10.32413/pjph.v13i2.1184>

20. Mansoor A, Mansoor E, Sana A, Javaid MM, Khan AS, Hussain K. Physiological and socio-economic satisfaction level of patients for acrylic and cast alloy dentures. *Pak J Physiol* 2023;19 (4): 6-10
21. Mansoor A, Mansoor E, Sana A, Javaid MM, Hussain K. Vaccination Status of Hepatitis-B Among Dental Patients Visiting a Public Health Sector of Islamabad. *Ann Pak Inst Med Sci.*2023; 19(3):356-360.
<https://doi.org/10.48036/apims.v19i3.929>
22. Ahmed N, Umar F, Saleem F, Iqbal Q, Haider S, Bashaar M. Treatment Outcomes of Severe Acute Malnutrition and Its Determinants Among Paediatric Patients in Quetta City, Pakistan. *J Multidiscip Healthc.* 2023 Dec 31:2809-21.
<https://doi.org/10.2147/JMDH.S428873>
23. Sultana R, Humayun S, Noor T, Humayun S, Zafar U. Impact of Thalassaemia on Quality of Life. 2016;6(4):156-60.
24. Aslamkhan M, Qadeer MI, Akhtar MS, Chudhary SA, Maryam M, Ali Z et al. Cultural consanguinity as cause of β -thalassemia prevalence in population. *medRxiv.* 2023:1-15.
<https://doi.org/10.1101/2023.06.01.23290856>
25. Khalid N, Noreen K, Qureshi FM, Mahesar M. Knowledge of thalassaemia and consanguinity: A multicenter hospital based retrospective cohort study from metropolitan city of Karachi, Pakistan. *Professional Med J* 2019; 26(9):1580-1586.
<https://doi.org/10.29309/TPMJ/2019.26.09.168>
26. Kahouei M, Kazemzadeh F, Mehdi J, Ahmedi Z. Hierarchy of Iranian parents' information needs and social seeking behaviour of infants suffering blood disease. *Social Sciences (Pakistan)*2016.;11(3):336-342
27. Bashir MB, Sadiq M, Khan M, Khan A, Ho A, Younas SM. Prevalence, level and factors associated with malnutrition in children under-five years of age and their parents' awareness about children nutrition in Quetta city. *Open J Pediatr Child Health.* 2021 Jun 5;6(1):020-5.
<https://doi.org/10.17352/ojpc.000033>
28. Hossain MJ, Islam MW, Munni UR, Gulshan R, Mukta SA, Miah MS et al. Health-related quality of life among thalassaemia patients in Bangladesh using the SF-36 questionnaire. *Scientific Reports.* 2023 May 12;13(1):7734.
<https://doi.org/10.1038/s41598-023-34205-9>