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Original Article

Economic Burden of Thalassemia on Parents of Thalassemic Children: A Multi-Centre Study

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Abstract

Objectives To determine the economic burden of thalassemia on parents of thalassemic children.

Study design, settings and duration: Descriptive nonprobability, purposive sampling done in PHRC Research Centres of Multan, Lahore, Islamabad, Karachi, Peshawar and Quetta from July 2013 to June 2014.

Patients and Methods: After taking informed written consent, parents/guardians of thalassemia major children were interviewed. All information was recorded on the pre-tested questionnaire. Data was entered and analyzed using SPSS version 11.

Results: A total of 600 guardians/ parents of the thalassemic children were included in the study. There were 57% boys and 43% girls with a mean age of 9.40 $\pm$ 5.66 years. Among them, 47.8% were from rural and 52.2 % from urban areas. Almost 71% children were transfusion dependent. The family history of cousin/interfamilial marriage was present in 78.2% while parental consanguinity was present in 72.8%. Only 1.7% parents got premarital screening for thalassemia. In private sector 56.8% had to pay nothing while others had to pay from Rs. 500 to Rs. 2000 per visit. Expenditure per month in private thalassemia centres showed that 57% had to bear no cost at all, 12.2% had to spend up to Rs. 1000, while 24.8% Rs. 1001 to 5000 and 6% had to pay more than Rs. 5000. In the government sector cost per visit in 35.5% was up to Rs. 500 while others had to pay between Rs. 501 to more than Rs. 2000. Monthly cost at government sector almost doubled. Total expenditure (private and government sector) per month was Rs. 9626 for each patient.

Conclusion: Total cost (both direct and indirect) for the management of thalassemia was quite high and this cost puts significant economic burden on the affected thalassemic families. This disease puts social, financial and psychological impacts on suffering families, so prevention-based strategies like premarital screening, prenatal diagnosis and genetic counseling should be adopted in Pakistan. A national screening project for thalassemia is the need of the day.

Key words: Economic burden, thalassemia, blood transfusion.

Introduction

Thalassemia major is the common genetic disorder in which life is impossible without regular blood transfusions.[1,2] This disease is one of the prime examples where prevention has got priority over the treatment. The preventive aspects of the disease have been adopted in some countries.[3] The pre-natal diagnosis is the mainstay in all these thalassemia control programs. Thalassemia are more prevalent around Mediterranean Sea, Turkey, Iran, India to South East Asia mainly Thailand and South China. In Italy and Greece, its prevalence is 5 to 15%.[4] Thalassemia major is a common hereditary disease in Iran affecting about 25000 children and about 3 million are carriers of the disease.[5] Maldives has a carrier rate of 18% while its prevalence is 16% in people of Cyprus and 3 to 8% in the population of China, Bangladesh, India and Malaysia.[4,6] In India, there are about 25 million carriers of β-thalassemia genes and over 9000 children of thalassemia are born every year.[7-9] Pakistan has the highest number of transfusion dependent thalassemic children worldwide. More than 80000 children are suffering from thalassemia major and there are about 8

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Authors Contribution

SS, AM and IT have done the conceptualization of project. AM, MAS, AM, ZA, FB, RF, TA did the data collection. AM and IT also did the literature search and SS did the statistical analysis. Drafting, revision and writing of the manuscript were done by SS and IT.

million carriers.[10] Furthermore, about 4000 to 5000 thalassemia major children are born each year in Pakistan.[11] The carrier rate of thalassemia in Pakistan is 5.3% however; it varies from 1.4 to 8% in different regions of the country, having highest prevalence along the Arabian Sea coast.[12] The disease is prevalent among different caste systems in Pakistan including Rajputs, Jatts, Arains, Shaikhs and Pathans who mostly emphasize on the consanguineous marriages.[13] Consanguineous marriages, high frequency of thalassemia gene in the population, low literacy rates, poor socio-economic status, lack of awareness, ethnic bindings are the contributing factors towards its high prevalence and persistence in the country.[14-15] The average life expectancy of thalassemia major patient in Pakistan is about 10 years [14] compared with developed countries such as Germany has more than 20 % patients older than 21 years of age.[16] Thalassemia is a continuous stress and economic burden on the suffering families and only a few studies are available in Pakistan on the economic burden of thalassemia major.[17-20]

A study from Thailand has reported annual cost of 950 USD for the treatment of one thalassemia patient. In this 59% is the direct medical cost and 24% is the indirect cost. In Sri Lanka the management of this disorder squeezes about 5% of total health budget.[21] In UK, the lifetime cost of thalassemia patient is 219068 to 803002 pounds which is the largest cost.[22] A study from Myanmar has calculated the annual estimated cost per thalassemia patient to be 1108.6 to 1208.7 KYATS.[23]

In Pakistan there are more than 80,000 children are suffering from thalassemia major, however, there is a scarcity of data available on economic burden of this disease. Therefore, the current study was designed to determine the economic burden of the disease on the families of thalassemic children. The results of this study will form the basis for the development of preventive strategies to control this disease. Ultimate measures will relieve the family stress, will save the economic losses and may help to reduce the disease burden.

Patients and Methods

Major thalassemia Centres of all four provinces and Federal capital city of Pakistan were included in this descriptive cross-sectional study. Ethical permission to conduct the study was taken from Institutional Ethical Review Committees of the participating institutions. After taking informed written consent, parents/guardians of the thalassemia major children who were registered in the thalassemia wards/centres were included in the study.

The parents/guardians were interviewed for their socio-economic status (low income= Rs. 12000 per month, middle income = 12001-35000 per month and high-income= more than Rs. 35000 per month),[24] ethnicity, caste, history of cousin marriages, history of screening before marriage, history of thalassemia in the family etc. A pre-tested questionnaire was used by the trained data collectors to collect data on average expenditures incurred upon transfusion, medication, consultation, lab investigations, traveling and economic losses etc.

Data were entered and analyzed using computer software SPSS version 11. Descriptive statistics was applied to calculate mean and standard deviation for the age of the patients. Frequencies and percentages were calculated for categorical study variables like gender, socio-economic status, occupation, mode of treatment, residential status, history of cousin marriages and premarital screening.

Results

A total of 600 respondents agreed to give their input in the survey. Of the care givers, 26.2% were fathers, 55.5% mothers, 9.3% grandmothers, 3% aunts and 3.8% sisters. Among thalassemic children 57 % were boys and 43 % girls. Mean age of these patients was 9.40 + 5.66 years. Of these 600 study cases, 47.8% were from rural areas and 52.2% were from urban areas. Seventy one percent belonged to poor, 25.5% to middle-income and only 3.5% to high-income families. Parental consanguinity was present in 72.8% patients while tradition of intra-familial marriages in the families of index cases was present in 78.2 %.

Only 1.7% got premarital screening for thalassemia, while 98.2% had no screening for thalassemia before marriage. Among the thalassemic children, 70.7% were dependent on blood transfusion. Of these 600 children, 65.6% children were diagnosed as having thalassemia at the age less than 6 months and 22.2% at 6-12 months of age, 5.8% at 12-24 months and 6.3% after the age of 24 months. Of these 600 families, 91.7% had 1-3 thalassemic children and 7.83% had 4-7 thalassemic children.

Monthly visits by the patients and care givers to the private thalassemia centres showed that 56.6% made no monthly visits, 32.6% visited 1-2 times, 9.7 % visited 3-4 times and 1% visited 5 times a month. The consultation fee paid to the private doctors ranged from no payment in 72.4 % to Rs. 500 in 24.5 % cases, while 3.1 % paid more than Rs. 500 per visit.

Medicinal expenditures per visit showed that 60.2% had no expenditure, 22.5% had to pay up to Rs. 500, 12.5% paid up to Rs. 501-1000 and 5% had to pay more than Rs 1000/visit.

Laboratory expenditures showed that 74% had to bear no laboratory expenditure, 17.83% had to pay up to Rs. 500 while 8.2% had to pay more than Rs. 500. Miscellaneous expenditure in majority i.e. 29.3% was up to Rs. 500 per visit while 5.8% had to pay more than Rs. 500.

Total cost per visit at the private thalassemia centers showed that 56.8% cases paid nothing, 11.3%

paid up to Rs. 500, 21.5% paid Rs. 501-2000 while, 10.3% paid more than Rs. 2000. Total expenditure in private sector was also calculated i.e. 57% had to pay nothing, 12.2% had to spend up to Rs. 1000, 24.8% had to spend Rs. 1001 to 5000 while 6% had to spend more than Rs.5000. City wise cost per month in private thalassemia centers is given in Table-1.

Table 1: City wise total expenditures in private thalassemia centers per month. (n=600)

City Name	*No Expenditure*	*< than Rs. 1000*	*Rs. 1001 – 5000*	*> than Rs. 5000*
Multan	45 (45%)	37 (37%)	18 (18%)	Nil
Lahore	98 (98%)	Nil	Nil	02 (02%)
Islamabad	22 (22%)	10 (10%)	58 (58%)	10 (10%)
Karachi	64 (64%)	19 (19%)	14 (14%)	3 (3%)
Quetta	82 (82%)	4 (4%)	13 (13%)	1 (1%)
Peshawar	31 (31%)	3 (3%)	47 (47%)	19 (19%)

In government sector, the frequency of visits per month was calculated and it showed that 64.7% had to make 1-2 visits and 18.7% had to visit 3-4 times/month. Government sector charges showed that 97.2% had to pay nothing, 2.5% paid up to Rs. 500 and only 0.33% had to pay more than Rs. 500 per visit. Medicinal charges per visit showed that 40.5% paid nothing, 49.3% had to pay up to Rs. 2000 and 10.2% paid more than Rs.2000. Laboratory charges in government sector showed that 81.5% had to pay nothing, 16.6% had to pay up to Rs. 500 and 2.33% paid more than Rs. 500/visit. Miscellaneous expenses per visit showed that 17.5% had no such expenses, 71% had expenses up to Rs. 500 and 11.5% spent more than Rs. 500. Cost per visit at government sector showed that 35.5% had to pay Rs. 500, 33.8% paid Rs. 501-2000 while, 14.6% paid more than Rs. 2000/visit. Cost per month at government sector when calculated showed that 37.5% had to pay up to Rs. 1000 while 35.5% paid up to Rs.1001 to 5000 and 10.5% paid more than Rs. 5000. City wise cost per month in government sector is given in Table-2.

Cost spent on associated illnesses per month revealed that 30% had to bear expenses up to Rs. 500 while 13.16% spent Rs. 501-1000 and 11.6% Rs. 1001-5000. Economic loss per visit when calculated showed that 18% had a loss of up to 500 rupees, 16.2% had a loss ranging from 501-1000 rupees, 32.5% ranging from Rs.1001-5000 and 2.16% more than Rs. 5000. Working days missed showed that 53.5% had to stay out of work for 1-2 days per month.

Distance from healthcare facility when inquired, showed that 20.6% had to travel less than 10 km, 23.3% had to travel between 11-20 km, 25.8% had to travel between 21-50 km, 18.5% had to travel between 51-100 km and 11.7% more than 100 km. Transport expenditures per visit in 14% were up to Rs. 100, in 57.3% it ranged between Rs. 101-500, in 17.7% it ranged between Rs. 501-1000 and in 11% it was more than Rs.1000. Time taken to reach health care facility was up to 1 hour in 19.8% cases while 19.2% spent between 1-2 hours, 19.7% spent 2-5 hours, 29% had spent 5-10 hours, 10.83% spent 11-24 hours and 1.5% more than 1 day. Time spent in the hospital in 96.7% cases ranged between 4-10 hours per visit.

Table 2: City wise total expenditures in government sector per month. (n=600)

City Name	*No Expenditure*	*< than Rs. 1000*	*Rs. 1001 – 5000*	*> than Rs. 5000*
Multan	1 (1%)	21 (21%)	48 (48%)	30 (30%)
Lahore	1 (1%)	60 (60%)	22 (22%)	17 (17%)
Islamabad	67 (67%)	13 (13%)	17 (17%)	3 (3%)
Karachi	7 (7%)	70 (70%)	23 (23%)	Nil
Quetta	Nil	42 (42%)	58 (58%)	Nil
Peshawar	23 (23%)	19 (19%)	45 (45(%)	13 (13%)

Discussion

Beta thalassemia is a most prevalent genetic blood disorder recognized in the world [15] and about 4% of the world population carries thalassemia gene.[25] This disorder results in considerable morbidity and mortality.[22] In thalassemia, male gender predominance has been reported in various studies. Similarly, in current study 57.2% were boys and 42.8% were girls. A similar trend was also reported by various studies previously. Qurat et al15 reported 65.7% versus 34.3% and Gurback et al [26] reported 55.5% versus 44.5%. The disease was more prevalent in low-income groups and poor families. As per classification of socio-economic status given in Economic Survey of Pakistan (2011-2012),[24] in the present study, overall 71% of the affected families were from the poor socioeconomic background. Similar findings have been reported by Qurat et al,[14] Shami et al [27] and Hafeez et al.[13] Moreover, the same family may have more than one thalassemic child. Qurat et al [14] have reported that 70% of the families had more than one beta-thalassemic child. Similarly, in this study, 91.7% had 1-3 thalassemic children in the same family and 7.8% had 4-7 thalassemic children. This familial tendency also increases the burden on the family and points towards the seriousness of interfamilial marriages among the sufferer families. Interfamilial marriages are the main source for its spread and persistence in Pakistani population. We also probed into family history, 78.2% gave a history of cousin/ interfamilial marriages and 72.8% parental consanguinity. Thalassemia is a condition where prevention has primary importance and has priority over treatment, for this mass thalassemia screening, prenatal diagnosis, familial and genetic counseling programs have been launched in many countries.[28-31] In this study, only 1.7% of the parents had undergone premarital screening and received counseling. Preventive control programs

have been successful in preventing thalassemia births by 96% in Cyprus, 62% in Italy and 52% in Greece from 1972 to 1984.[32] Therefore, more concentration and attention has to be directed towards the affected families and this can save them from future hardships. Premarital screening can identify the individuals at high risk and an intensive preventive program like pre-natal diagnosis can also be offered to these couples.[33] If both parents are carriers of thalassemic gene there are 25% chances in each pregnancy resulting in a child with thalassamia major, 50% chance to give birth to a carrier child and 25% child with the normal gene, so premarital screening will be really important to meet the future challenges of thalassemia. As far as the economic burden is concerned, the patient's caregivers were asked about the number of visits of the thalassemic children to hospitals. If we compare the cost of consultation, it is encouraging that government sector provided consultation free of cost in 97.2% of the cases, while in private sector 72.6% of the sufferers were able to get consultation services free of cost. The cost of hospital charges, medicine charges, lab expenditure and miscellaneous expenditures etc. were also inquired. Total cost per visit and per month was also calculated. Average cost per visit per patient in public sector was Rs. 1104 while it was Rs. 718 in private thalassemia centres. Less expenditures/ free consultation in private thalassemia centres were due to collaboration of different blood donor societies and NGOs which facilitate such patients. In Myanmar, the annual cost per patient was Kyats 1108.6 to 1208.7 the averaged annual cost borne by the patient's families were Kyats 107 (0 – 1509).[23] The average cost per month was Rs. 2118 in Government sector while it was Rs. 1340 in private sector. A study conducted by Riewpaiboon et al [19] reported from Thailand the average annual cost per patient was 950 USD and direct medical cost accounted for 59% of the total cost in thalassemic children while annual cost per patient in our study when changed in USD, is 1070 $ which is comparable to that of Riewpaiboon et al.[19]

Our study results have also indicated that people had to travel long distances to reach to the government sector for transfusion purpose and chelation therapy. This was again exerting extra financial burden on the sufferer families because majority of them were using public transport and had to pay high fare to reach there and consumed long hours, moreover 53.5% of the attendants had to miss 1-2 working days per month and the average economic loss in terms of work days missed was Rs.1133/- per month which can be saved if such facilities are provided to them at nearby healthcare centres. The total indirect average cost was Rs.3468/-. Total cost (direct and indirect) was Rs.6926/- per month for each patient. In India, approximate expenditures per patient came out to be Rs. 2500/- per month.[7] Although government sector provides majority of services free of cost like consultation, blood transfusion and laboratory tests but these families had to bear certain charges like purchase of medicines from the market and miscellaneous expenditures like food etc. In some big cities like Islamabad and Karachi some NGOs were providing transfusion facilities at nominal prices so a majority of people preferred to go there but in other cities, these families had to come to government sector for this purpose.

Keeping in view the economic burden, its social and psychological effects public awareness about the disease should be addressed at every level. Extended family screening of thalassemia patients, genetic counseling of individual at risk and couples, prenatal diagnosis of the suspected fetus should be emphasized. Prevention is cheaper and fruitful as the cost of treatment is 10 times the cost of prevention[10] than care and management. National thalassemia program in Iran over 5 years period has dropped the number of new cases of thalassemia from 1200 to just 70.[10] Therefore, there is need to carry out a screening project in Pakistani population, at least among affected families followed by awareness campaigns on long term basis. Based on our observations national beta thalassemia prevention program will have cost-benefit effects. In addition to the financial savings, saving of hundreds of blood units and work hours, all will help towards economic strengthening.

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Conflict of interest: None declared.

References

1. Galanello R, Origa R. Beta Thalassemia. Orphanet J Rare Dis 2010;5:11.
2. Muncie HL, Campbell J. Alpha and beta thalassemia. Am Fam Physician 2009; 80(4):339-44.
3. Iqbal I. Prevention of thalassemia in Pakistan. Nishtar Med J 2009;1(2):1-3.
4. Lonnginotti M, Pistidda P, Offiano L, Guiso L, Frogheri L, Dore F, et al. A 12-year preventive program for beta-thalassemia in Northern Sardinia. Clin Genet 1994;46(3):238-43.
5. Ghotbi N, Tsukatani T. An economic review of the national screening policy to prevent thalassemia major in Iran. Kyoto Institute of Economic Research Kyoto University 2002. Discussion paper No. 562.

6. Eleftheriou A, Angastiniotis M. A Report on Thalassaemia for the Association of South East Asian Nations (ASEAN); 2013. Accessed on 08th May 2015) Available from URL: https://www.thalassaemia.org.cy/uploads/1447879525asean-ifreportonhaemoglobinopathies1308023.pdf
7. Singh K, Singh K, Singh R, Kaur D. Financial burden on the families of transfusion dependent thalassemic children. Pediatric Oncall J 2013;10(1). DOI: 10.7199/ped. oncall.2013.2
8. Vaz F, Banerjee M, Kapadia C, Natrajan PG, Yagnik H, Gangal S. Prenatal diagnosis of β-thalassaemia and other haemoglobinopathies in India. Prenat Diagn 2000;20:194-201.
9. Verma IC, Choudhry VP, Jain PK. Prevention of thalassemia: a necessity in India. Indian J Pediatr 1992;59:649-54.
10. Shaikh Z. Thalassemia: Pakistan's fight to eradicate this condition. [. Accessed on 08th May 2015) Available from URL:http://www.aglobalvillage.org/journal/issue3/global_ health_and_ development/thalassemia.
11. Saleem M, Ahmed S, Khatak MF. An overview of thalassaemia in Pakistan. Proceedings of 4th International Conference. Peshawar: Pakistan Association of Pathologists, 1996:76.
12. Ahmed S, Saleem M, Sultana N, Raashed Y, Waqar A, Anwar M, et al. Prenatal diagnosis of β-thalassemia in Pakistan: experience in a Muslim Country. Prenat Diagn 2000;20:378-83.
13. Hafeez M, Aslam M, Ali A, Rashid Y, Jafri H. Regional and ethnic distribution of beta thalassemia mutation and effect of consanguinity in patients referred for prenatal diagnosis. J Coll Phys Surg Pak 2007;17:144-47.
14. Qurat-ul-Ain LA, Hassan M, Rana SM, Jabeen F. Prevalence of β-thalassemic patients associated with consanguinity and anti-HCV- antibody positivity-a cross sectional study. Pak J Zool 2011;43(1):29-36.
15. Baig SM, Rabbi F, Hameed U, Qureshi J, Mahmood A, Bukhari SH, et al. Molecular characterization of mutations causing beta thalassemia in Faisalabad, Pakistan using amplification refractory mutation system (ARMS-PCR). Ind J Hum Genet 2005;11:80-3.
16. Cario H, Stahnke K, Sander S, Kohne E. Epidemiological situation and treatment of patients with thalassemia major in Germany: results of the German multicentre beta thalassemia study. Ann Hematol 2000;79:7-12.
17. Siddiqui SH, Ishtiaq R, Sajid F, Sajid R. Quality of life in patients with thalassemia major in a developing country. J Coll Physicians Surg Pak 2014;24(7):477-80.
18. Sattari M, Sheykhi D, Nikanfar A, Pourfeizi AH, Nazari M, Dolarkhah R, et al. The financial and social impact of thalassemia and its treatment in Iran. Pharmaceutical Sci 2012;18(3):171-6.
19. Riewpaiboon A, Nuchprayoon I, Torcharus K, Indaratna K, Thavorncharoensap M, Ubol BO. Economic burden of beta-thalassemia/Hb E and beta-thalassemia major in Thai children. BMC Res Notes 2010;3:29.
20. Clarke SA, Skinner R, Guest J, Darbyshire P, Cooper J, Shah F, et al. Health-related quality of life and financial impact of caring for a child with thalassaemia major in the UK. Child Care, Health and Development 2010;36:118-22.
21. de Silva S, Fisher CA, Premawardhena A, Lamabadusuriya SP, Peto TE, Perera G et al. Thalassemia in Sri Lanka: implications for the future health burden of Asian populations. The Lancet 2000;355:786-91.
22. Karnon J, Zeuner D, Brown J, Ades AE, Wonke B, Modell B.. Lifetime treatment costs of beta thalassemia major. Clin Lab Haematol 1999;21(6):377-85.
23. Han MM, Han KE, Myint KT. Thalassemia in the outpatient department of the Yangon Children's Hospital in Myanmar: cost analysis of the day-care-room services for thalassemia. Southeast Asian J Trop Med Public Health 1992;23(2):273-7.
24. Economic Survey of Pakistan. Finance Division, Government of Pakistan. Chapter Inflation 2011-2012;100.
25. Koren A, Profeta L, Zalman L, Palmor H, Levin C, Zamir RB, et al. Prevention of β thalassemia in Northern Israel - a cost-benefit analysis. Meditter J Hematol Infect Dis 2014;6(1):e2014012. DOI 10.4084/MJHID.2014.012.
26. Gurbak M, Sivasli E, Coskun Y, Bozkurt AI, Ergin A. Prevalence and hematological characteristics of β-thalassemia trait in Gaziantep urban area, Turkey. Pediatr Hematol Oncol 2006;23:419-25.
27. Shami SA, Tariq AK. Consanguinity and thalassemia. Pak J Zool 1999;31:105-6.
28. Karimi M, Jamalian N. Sociocultural challenges of thalassemia birth in Islamic developing countries. J Pediatr Hematol Oncol 2008:30(4):335.
29. Scriver CR, Bardanis M, Cartier L, Clow CL, Lancaster GA, Ostrowsky JT. Beta-thalassemia disease prevention: genetic medicine applied. Am J Hum Genet 1984;36:1024-38.
30. Hendy J. Prevention of thalassemia in Australia. Southeast Asian J Trop Med Public Health 1999;30(Suppl 2):94-6.
31. Ko TM, Xu X. Molecular study and prenatal diagnosis of alpha- and beta-thalassemias in Chinese. J Formos Med Assoc 1998;97(1):5-15.
32. Kuliev AM. Thalassemia can be prevented. World Health Forum 1986;7:286-90.
33. Mitchell JJ, Capua A, Clow C, Scriver CR. Twenty year outcome analysis of genetic screening programs for Tay-Sachs and beta thalassemia disease carriers in high schools. Am J Hum Genet 1996;59(4):793-8.