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Original Research Article

Assessment of Psychosocial Impact on Parents of Thalassemic Children

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Abstract: Thalassaemia is an autosomal recessive hemoglobinopathy which is an increasingly serious public health issue in India. Chronic diseases like beta thalassemia create a burden on parents by means of frequent hospital visits, social and financial stresses which ultimately lead to impairment in multiple aspects of their lives. The aim is to assess the psychosocial impact of thalassemia on parents of affected children. This comparative study was conducted at Pediatric department of a teaching tertiary care hospital in Pune city. PedsQL™ Family Impact Module was used to assess psychosocial impact of thalassemia on parents of affected children and was compared with parents of children not affected with any chronic illnesses. Statistical analysis: Numerical data is expressed as mean ± SD and categorical data is expressed as number and percentage. Student two tailed t test is used to compare 02 independent data groups. P value for statistical significance is set at <0.05 for 2 tailed tests. Total 56 parents were included in this study, of which 28 were parents of thalassemic children and 28 were parents of children not suffering from any chronic illnesses. Total score, parent health-related quality of life summary score and family functioning summary score were affected significantly with a p value <0.0001. Thalassemia has significantly impaired the psychosocial aspect of parents of affected children.
Keywords: Psychosocial impact, Thalassemia, Parents, Assessment.

INTRODUCTION:

Thalassaemia is an autosomal recessive hemoglobinopathy characterized by partial or no production of alpha or beta globin chains which form part of the structure of the haemoglobin in the red blood cells [1]. Thalassemia is an increasingly serious public health problem [2, 3]. The life expectancy and survival of these patients have increased dramatically over previous decades through introduction of regular blood transfusion therapy and iron-chelating therapies [4-6]. Chronic diseases like beta thalassemia create a burden on parents by means of frequent hospital visits, distress regarding child's future and health which leads psychological, social and financial stresses which ultimately affects the well-being of the patient [7]. In developing countries such as India, leading cause of death in thalassemic patients is non-compliance with the treatment due to psychological and social factors [8].

Health Related Quality of Life (HRQoL) measurement is a multidimensional concept that focuses on the impact of the disease and its treatment on the well being of an individual. The measures are seen as ways of capturing patients' perspectives of their disease and treatment, their perceived need for healthcare and their preferences for treatment and disease outcomes [9]. Previous studies reveal that quality of life of parents with children affected from chronic illnesses is affected [10]. Thalassemia and its complications create a major psychosocial and financial impact on patient's families causing emotional burden, financial constraints, misery and complexity with social integration [11]. This leads to deterioration of parents' health. Parents of thalassemic patients show impairment in physical health, psychological health and quality of health [10].

Parents impact on a child's physical, emotional and mental well being and affecting numerous areas of a child's life, including health, development, academic progress and quality of life. Taking into account the above factors, it is essential to maintain parents' health for betterment of the family and development of the child. Hence this study aims to determine the psychosocial impact of thalassemia on the parents of children suffering from beta thalassemia major compared to the parents of healthy children.

MATERIALS AND METHODS:

This comparative study included a total of 56 participants including parents of 28 thalassemic patients from the age of 3 to 14 years attending the Pediatric OPD of a tertiary care teaching hospital in Pune city. The control was taken as parents of 28 healthy children not suffering from any chronic illnesses. The assessment was done using PedsQL Family impact Module questionnaire given to all the parents of patients

and control. An informed written consent was obtained from all parents of patients and control prior to inclusion in the study. The study was carried out from June 2014 to July 2014.

Inclusion criteria:

- Parents of diagnosed cases of beta thalassemia major receiving regular blood transfusions. Diagnosis had been made according to their haemoglobin electrophoresis results.

The patients' demographic data including age, sex and educational status were recorded.

Research Instrument:

PedsQL™ Family Impact Module [12] Scale is a 36-item scale encompassing 6 scales measuring parent self-reported functioning:

1) Physical Functioning (6 items)
2) Emotional Functioning (5 items)
3) Social Functioning (4 items)
4) Cognitive Functioning (5 items)
5) Communication (3 items)
6) Worry (5 items)
7) Daily Activities (3 items)
8) Family Relationships (5 items).

The PedsQL™ Family Impact Module was developed as a parent-report instrument. A 5-point response scale is utilized (0 = never a problem; 4 = always a problem). Items are reverse-scored and linearly transformed to a 0–100 scale (0 = 100, 1 = 75, 2 = 50, 3 = 25, 4 = 0), so that higher scores indicate better functioning (less negative impact). Scale Scores are computed as the sum of the items divided by the number of items answered (this accounts for missing data). If more than 50% of the items in the scale are missing, the Scale Score is not computed.

This Module yields 3 summary scores:

- Total score
- Parent health-related quality of life summary score
- Family functioning summary score

The total score is comprised of the average of the responses to all items in the questionnaire. The Parent HRQL summary score is determined by averaging the responses to the 20 items that make up the physical, emotional, social and cognitive functioning scales noted above. The family functioning summary score is determined by averaging the responses to the 8 items that make up the daily activities and family relationships scales. This scale has been shown to be reliable and valid in smaller studies of children with complex special health care needs and children with cancer [12, 13].

In this study, we have calculated the following:

- Total score
- Parent health related quality of life summary score
- Family functioning score
- Worry score

All the scores were compared to the control population of parents of 28 pediatric patients not suffering from any chronic illness.

STATISTICAL ANALYSIS:

The results obtained were tabulated in Microsoft excel sheet. Descriptive analysis was done for all data. Numerical data is expressed as mean ± SD and categorical data is expressed as number and percentage. Student two tailed t test is used to compare 02 independent data groups. P value for statistical significance is set at <0.05 for 2 tailed tests.

Ethical considerations:

The study was conducted according to the Declaration of Helsinki; the protocol was reviewed and approved by the institutional ethics committee of the institute. Assent was taken as well as informed consent was obtained from the study subject's parents or guardian.

RESULTS:

Total 56 parents were included in the study; out which 28 were parents of thalassemic patients and 28 were parents of healthy children. Fifty four parents completing the PedsQL™ Family Impact Module were the subject's mothers, except 2 cases which were answered by the fathers. Table 1 consists of domains Physical, Emotional, Social, and Cognitive, Worry score, family relations, Daily activities and Communication. The differences between the scores for parents of thalassemic children and parents of healthy children is found to be statistically significant and p value for the scores is calculated to be <0.0001.

Table 1: Comparision of Scores of Domains of Quality of life scale

1.	Physical	74.1	88.98	<0.0001;HS
2.	Emotional	65.53	86.6	<0.0001;HS
3.	Social	67.63	95.08	<0.0001;HS
4.	Cognitive	73.75	91.78	<0.0001;HS
5.	Worry	60.17	93.39	<0.0001;HS
6.	Family Relations	65.53	99.1	<0.0001;HS
	Daily Activities	63.68	97.9	<0.0001;HS
	Communication	78.85	94.02	<0.0001;HS

*HS= Highly Significant

Table 2 consists of HRQOL, Family functioning score and Total score. The differences between the scores for cases and control is found to be statistically significant and p value for the scores is calculated to be <0.0001. The PedsQL™ Family Impact Module Total scale score for cases is 68.66 ± 3.76 and for control is 93.36 ± 2.25. Health-related Quality of Life (HRQOL) of parents of thalassemic children was found to be 70.25 ± 4.45 and parents of healthy children was found to be 90.61 ± 4.17. Family functioning score of parents of thalassemic children was found to be 64.61 ± 8.70 and parents of healthy children was found to be 98.5 ± 1.85.

Table 2: Comparison of Scores of HRQOL, Family functioning & Total score

1.	HRQOL	70.25	90.61	<0.0001; HS
2.	Family Functioning	64.61	98.5	<0.0001; HS
3.	Total	68.66	93.36	<0.0001; HS

*HS= Highly Significant

DISCUSSION:

The existence of a life threatening or long-lasting disease in a child is a condition that causes stress in parents and that can predispose them to psychosocial disorders [14]. The life expectancy and prognosis of thalassemic patients has greatly improved due to modern treatments, [15] but the same treatments being life-long measures create an impact on the life of these patients. The life-long measures are expensive and needs proper adherence for significant results; this creates a direct pressure on the parents of thalassemic children. Thus, it is important to assess the psychosocial burden on the caretakers of thalassemic patients. Keeping this in mind, this study was carried out to know the psychosocial stress that parents of thalassemic patients face.

This study was conducted on parents of thalassemic patients attending Pediatric OPD of teaching tertiary care hospital in Pune and control group were parents of children attending same hospital for minor ailments and not suffering from any chronic illnesses. The Quality of life of thalassemic children and parents is affected due to long term complications of the disease. As the disease requires regular blood transfusions as treatment, a psychological [16] and economic burden is borne by the families. According to results of this research, the worry score was most impaired than any other parameters. The worry score included questions regarding effectiveness of treatment, side effects, future of child etc. It was also found in the study that HRQOL of the parents were affected, with the emotional domain most prominently affected.

The parents of thalassemic children often felt vulnerable due to chronicity of illness and no definitive cure. Due to excessive financial and psychological burden, parents were found to face difficulties in leading a normal family life and creating a positive atmosphere at home. These aspects are reflected in the lower family functioning scores of the cases compared to the control group. Previous studies have similar results showing adversely affected quality of life of caregivers of thalassemic patients [17].

CONCLUSION:

The study concludes that there is significant impact on parents of thalassemic children especially concerning the child's future. The present study also came to an impression that the parents of affected children had issues with other family members with respect to understanding of the gravity of the child's health situation and future concerns. According to this study, above two factors seem to be the cause for significant emotional impairment compared to other domains in parents of the affected children.

SUGGESTIONS:

There is a need to tackle anxiety and worry among parents, as behaviour of parents, particularly mothers, affects their children's health [18].

- General Practitioners, Paediatricians and Primary healthcare physicians can play a key role in promoting childcare which can be delivered through supporting better parenting [19].
- Through this study, we recommend that parental counselling should be done. As by thorough knowledge of disease and treatment options, parents can equip themselves to tackle the effects of thalassemia.
- As health and income are related [19] parents of patients should also be connected to governmental and nongovernmental organizations, which provide care at subsidized rates, to help them on an economic front.

REFERENCES

1. Clegg JB, Weatherall DJ. Thalassemia and malaria: new insights into an old problem. Proceedings of the Association of American Physicians. 1999 Jul 1; 111(4):278-82.
2. Vullo R, Modell B, Georganda B: What Is Thalassaemia? 2nd edition. The Thalassaemia International Federation; 1995.
3. Weatherall D. The thalassemias: the role of molecular genetics in an evolving global health

problem. The American Journal of Human Genetics. 2004 Mar 31; 74(3):385-92.
4. Brittenham GM, Griffith PM, Nienhuis AW, McLaren CE, Young NS, Tucker EE, Allen CJ, Farrell DE, Harris JW. Efficacy of deferoxamine in preventing complications of iron overload in patients with thalassemia major. New England Journal of Medicine. 1994 Sep 1; 331(9):567-73.
5. Telfer P, Coen PG, Christou S, Hadjigavriel M, Kolnakou A, Pangalou E, Pavlides N, Psiloines M, Simamonian K, Skordos G, Sitarou M. Survival of medically treated thalassemia patients in Cyprus. Trends and risk factors over the period 1980-2004. Haematologica. 2006 Jan 1; 91(9):1187-92.
6. Olivieri NF, Brittenham GM. Iron-chelating therapy and the treatment of thalassemia. Blood. 1997 Feb 1; 89(3):739-61.
7. Porter JB, Davis BA. Monitoring chelation therapy to achieve optimal outcome in the treatment of thalassaemia. Best Practice & Research Clinical Haematology. 2002 Jun 1; 15(2):329-68.
8. Ratip S, Modell B. Psychological and sociological aspects of the thalassemias. InSeminars in hematology 1996 Jan (Vol. 33, No. 1, p. 53).
9. Ansari S, Baghersalimi A, Azarkeivan A, Nojomi M, Rad AH. Quality of life in patients with thalassemia major. Iranian journal of pediatric hematology and oncology. 2014; 4(2):57.
10. Ali, S., Sabih, F., Jehan, S., Anwar, M., and Javed, S. Psychological distress and coping strategies among parents of beta-thalassemia major patients. International Proceedings of Chemical, Biological and Environmental Engineering 2012; 27: 124-128.
11. Mazzone L, Battaglia L, Andreozzi F, Romeo MA, Mazzone D. Emotional impact in β-thalassaemia major children following cognitive-behavioural family therapy and quality of life of caregiving mothers. Clinical practice and epidemiology in mental health. 2009 Feb 23; 5(1):5.
12. Varni JW, Sherman SA, Burwinkle TM, Dickinson PE, Dixon P. The PedsQL™ family impact module: preliminary reliability and validity. Health and quality of life outcomes. 2004 Sep 27; 2(1):55.
13. Scarpelli AC, Paiva SM, Pordeus IA, Varni JW, Viegas CM, Allison PJ. The Pediatric Quality of Life Inventory™ (PedsQL™) family impact module: reliability and validity of the Brazilian version. Health and Quality of Life Outcomes. 2008 May 20; 6(1):35.
14. Aziz K, Sadaf B, Kanwal S. Psychosocial problems of Pakistani parents of Thalassemic children: a cross sectional study done in Bahawalpur, Pakistan. BioPsychoSocial medicine. 2012 Aug 1; 6(1):15.
15. Borgna-Pignatti CA, Rugolotto SI, De Stefano P, Zhao HU, Cappellini MD, Del Vecchio GC, Romeo MA, Forni GL, Gamberini MR, Ghilardi RO, Piga AN. Survival and complications in patients with thalassemia major treated with transfusion and deferoxamine. Haematologica. 2004 Jan 1; 89(10):1187-93.
16. Assi Obaid Kareem, Psychological problems associated with Thalassemia in Diyala province, Iraq. The Swedish Journal of scientific Research; 2014; 1(3); 6-10
17. Shaligram D, Girimaji SC, Chaturvedi SK. Quality of life issues in caregivers of youngsters with thalassemia. Indian journal of pediatrics. 2007 Mar 1; 74(3):275-8.
18. Case A, Paxson C. Parental behavior and child health. Health Affairs. 2002 Mar 1; 21(2):164-78.
19. Hoghughi M. The importance of parenting in child health. British Medical Journal. 1998 May 23; 316:1545-1547.