

## Original Article

# Health related quality of life and family functioning of parents having children suffering from thalassaemia

\* Chowdhury T<sup>1</sup>, Chowdhury ZR<sup>2</sup>, Chowdhury M<sup>3</sup>, Mollah MS<sup>4</sup>, Benzamin M<sup>5</sup>

### Abstract:

**Background:** Thalassaemia is a hereditary blood disorder without an effective cure in majority. Despite recent advances in the management of thalassaemia, people living in developing countries do not receive satisfactory treatment. Parents of these children have many problems in various aspects of physical, emotional, social and communications. The objective of this study was to assess the HRQOL and family functioning of parents having children with thalassaemia in comparison to the parents of healthy children.

**Methods:** This case-control study was conducted in the Department of Paediatrics, Sylhet MAG Osmani Medical College Hospital during the period of January 2022 to June 2022. Data were collected by using standard self-administered multi-dimensional questionnaire of the paediatric quality of life inventory (PedsQLTM) 4.0 FIM 2.0 Bengali version. A total of 50 parents of children with thalassaemia were enrolled as cases. Another 50 age and sex matched parents of healthy children were selected as controls. In both studied groups parents were free from any chronic diseases. Descriptive and analytical statistics were performed to compare scores between the two groups (case and controls).

**Results:** Baseline characteristics of cases and controls regarding age, sex, educational status and socio-economic conditions were comparable. PHRQOL summary scores in cases and controls were  $56.67 \pm 16.34$  and  $85.53 \pm 14.24$  respectively. The FaF summary scores were  $68.46 \pm 15.87$  and  $78.64 \pm 11.79$  respectively. It has been observed that both summary scale scores were significantly lower ( $p < 0.01$ ) in case group.

**Conclusion:** HRQOL and family functioning of parents having children with thalassaemia were significantly lower than the parents of healthy children.

**Keywords:** Quality of life, Family functioning, Thalassaemic children.

JSWMC 2023 [13(02)] P: 49-52

### Introduction:

Worldwide, thalassaemia is an increasing serious public health problem due to the high prevalence<sup>1</sup>.

1. Dr. Tanjina Chowdhury, Assistant Professor, Department of Paediatrics, Sylhet MAG Osmani Medical College .
2. Dr. Ziaur Rahman Chowdhury, Assistant Professor, Department of Paediatrics, Sylhet MAG Osmani Medical College .
3. Dr. Minakshi Chowdhury, Assistant Professor, Department of Paediatrics, Sylhet MAG Osmani Medical College .
4. Dr. Muhammad Solaiman Mollah, Assistant Professor, Department of Paediatrics, Sylhet MAG Osmani Medical College .
5. Dr. Md Benzamin, Registrar, Paediatrics Gastroenterology and Nutrition, Department of Paediatrics, Sylhet MAG Osmani Medical College

**Corresponding author: DR. Tanjina Chowdhury,** Assistant Professor, Department of Paediatrics, Sylhet MAG Osmani Medical College .  
Email: [tanjina0407@gmail.com](mailto:tanjina0407@gmail.com)

Thalassaemia is an autosomal recessive disorder characterized by partial or no production of alpha or beta globin chains which form part of the structure of the hemoglobin in the red blood cells and ultimately results in anaemia<sup>2,3</sup>. Patients with  $\beta$ -thalassaemia major require regular blood transfusion and iron chelation therapy to survive<sup>4</sup>. Parents of thalassaemic children have many concerns regarding their child's health, future outcome, frequent hospital visits for blood transfusion and other associated complications<sup>5</sup>. They feel depressed, worried, helpless and experience high levels of physical and mental stress<sup>6</sup>.

The prevalence of thalassaemia in Bangladesh is high but accurate data is sparse. Traits of different haemoglobin disorders are about 6-12% of the population. Severely affected children with beta-thalassaemia major and HbE-beta thalassaemia are about 60,000- 70,000.<sup>7</sup>

The importance of quality-of-life (QOL) as part of overall health is supported by the world health organization (WHO) definition of health as merely the absence of disease but a state of physical, emotional and social wellbeing. The

WHO defined “the quality of life (QOL) as an individual’s perception of their position in life in the context of the cultures and value system in which they live and in relation to their goals, expectations, standards and concerns.” When QOL is used in medical practice in the assessment of the state of the individual is known as health-related quality of life (HRQOL)<sup>8</sup>. Family functioning refers to the social and structural properties of the global family environment <sup>8,9</sup>. Parent’s HRQOL and family functioning may be impaired by the disease process of the child having transfusion dependent thalassaemia. The purpose of the study is to access all the aspects of HRQOL and family functioning of parents having children suffering from thalassaemia.

### Methodology

This case-control study was conducted in department of Paediatrics ,Sylhet MAG Osmani Medical college Hospital (SOMCH) from January 2022 to June 2022.Total fifty(50) parents of children with thalassaemia receiving blood transfusion for more than six months were included in this study. They were regarded as group A. Demographic data regarding information about age, sex, educational level, household income etc. were collected from parents. Medical data regarding diagnosis, treatment status etc. were obtained from the patient’s medical record. Then Bengali version paediatric quality of life inventory (PedsQLTM)4.0 family impact module 2.0 generic scale was used to generate score of QOL and family functioning. PedsQL family impact module which consists of 36 items and have 6 subscales measuring the parents self-reported functioning: Physical functioning (6 items),Emotional functioning (5 items), Social domain (4 items),Cognitive functioning (5 items), Worry (5 items), Communication domain (3 items); as well as 2 subscales measuring the parent- reported family functioning: daily activities (3 items),relationship of the family domain (5 items). The total score is 144. The PedsQL total score is calculated by summation of the 36 item scores divided by the number of items answered.

For comparison with healthy subjects the data were collected from age and sex matched 50

parents of healthy children from nearby school and community using same scale. They were regarded as group B. Informed written consent were obtained from both group A and B prior to participating in the study. Data was collected through personal interview.

Data were analyzed with SPSS (statistical package for social sciences) version 22. Quantitative data were expressed as mean and standard deviation and comparison was done by unpaired t-test. Qualitative data was expressed by frequency and percentages and comparison was carried by Chi-square (x<sup>2</sup>) test. A p-value of <0.05 was considered statistically significant.

### Results

In this study 50 parents having children suffering from thalassaemia (group A) and 50 parents of healthy children (group B) were interviewed. This demographic data is presented in table 1.

**Table 1: Baseline characteristics of parents of children with thalassaemia and parents of healthy children**

| Parameter                  |                     | Case     | Control   | P value |
|----------------------------|---------------------|----------|-----------|---------|
| Age (year)                 | 20-30               | 9 (18%)  | 12 (24%)  | 0.51    |
|                            | 30-40               | 32 (64%) | 28 (56%)  |         |
|                            | >40                 | 9 (18%)  | 10 (20%)  |         |
|                            | Mean ± SD           | 34±4.9   | 33.6±4.02 |         |
|                            | Male                | 8 (16%)  | 9 (18%)   |         |
| Sex                        | Female              | 42 (84%) | 41 (82%)  | 0.14    |
|                            | Illiterate          | 5 (10%)  | 3 (6%)    |         |
| Educational status         | Primary             | 17 (34%) | 15 (30%)  | 0.92    |
|                            | SSC                 | 20 (40%) | 22 (44%)  |         |
|                            | HSC and above       | 8 (16%)  | 10 (20%)  |         |
|                            | Low income          | 9 (18%)  | 6 (12%)   |         |
| Socio-economical condition | Lower middle income | 33 (66%) | 34 (68%)  | 1.58    |
|                            | Upper middle income | 8 (16%)  | 10 (20%)  |         |

Baseline comparisons using t test and x<sup>2</sup> test did not show statistical differences between the two groups in term of age, sex, level of education and socioeconomic condition (P>0.05)

**Table 2 : Comparison of PHRQOL by using PedsQLTM 4.0 FIM 2.0 scores between cases and controls in different functioning categories.**

| Categories            | Cases n=50<br>Mean±SD | Controls n=50<br>Mean±SD | P-value |
|-----------------------|-----------------------|--------------------------|---------|
| Physical Functioning  | 58.2±23.34            | 82.24±17.62              | <0.001  |
| Emotional Functioning | 50.8±26.36            | 88.02±12.96              | <0.001  |
| Social functioning    | 52.24±24.59           | 83.9±13.96               | <0.001  |
| Cognitive functioning | 66.53±26.36           | 83.7±16.15               | <0.001  |
| Communication         | 65.00±19.21           | 87.1±10.86               | <0.001  |
| Worry                 | 47.30±16.31           | 88.26±20.37              | <0.001  |
| PHRQOL summary score  | 56.67±16.34           | 85.53±14.24              | <0.001  |

Table 2 showed the comparison of scores in parents HRQOL Summary Score was significant for the cases compared to the controls. All of six individual domains of PHRQOL showed significantly lower values in each category among the cases as compared with the controls. Data were analyzed using t- test.

**Table 3: Comparison of FaF Summary Score by using PedsQITM 4.0 FIM 2.0 between cases and controls in different functioning categories.**

| Categories           | Cases (n=50)<br>Mean ± SD | Controls (n=50)<br>Mean ± SD | P-value |
|----------------------|---------------------------|------------------------------|---------|
| Daily Activities     | 63.46±16.30               | 65.98±18.81                  | 0.71    |
| Family Relationships | 73.46±20.95               | 91.3±9.8                     | <0.001  |
| FaF Summary Score    | 68.46±15.87               | 78.64±11.79                  | <0.001  |

Data were analyzed using ‘ t- test’

Table 3 showed the scores in Family Functioning Summary Score significantly lower value for the cases compared to the controls. Individual domain of Family Relationships was significant for the cases compared to the controls but Daily Activities score was insignificant (P>0.05).

### Discussion

The existence of a chronic disease like thalassaemia in children causes physical and psychological stress in parents and that can predispose them to psychological disorders <sup>1</sup>. The clinical management of thalassaemia has improved extensively in last decade even in

developing countries. But few attempts are made to up lift the quality of life among patients and family <sup>10</sup>. Total 50 parents having children suffering from thalassaemia (group A) and 50 parents of healthy children (group B) were studied. Among them 42(84%) of group A and 41(82%) of group B were female. It was difficult to interview the fathers of children due to some factors like living abroad, engaged in profession etc.

In this study parents having children suffering from thalassaemia had lower HRQOL and FaF scores compared to parents of similar backgrounds who had healthy children. In the current study mean physical functioning scores for group A and group B were 58.2±23.34 and 82.24±17.62 respectively, emotional functioning scores were 50.8±26.36 and 88.02±12.96 respectively, social functioning scores were 52.24±24.59 and 83.9±13.96 respectively, cognitive functioning scores were 59.75±19.73 and 90.75±17.23 respectively, communication scores were 65.00±19.21 and 87.1±10.86 respectively, worry scores were 47.30±16.31 and 88.26±20.37 respectively. Scores of all domains of HRQOL showed significantly lower values (p<0.001) for group A than group B. Among them the lowest scores were found in worry and emotional functioning. Similar findings were found in a study by (Sandra 2015) at St. John’s Medical College Hospital (SJMCH), Bangalore <sup>11</sup>. Sharma et al al also found significantly low scores (p<0.001) for all the domains of HRQOL in parents having children with thalassaemia than parents having healthy children <sup>12</sup>.

In this study Family Functioning of parents of thalassaemic children (Group A) and parents of healthy children (Group B) were compared. The mean daily activities scores were 63.46±16.34 and 65.98±18.81 respectively which is statistically not significant (p>0.05). Family relationship scores were 73.46±20.75 and 91.3±9.8 respectively which is statistically significant (p<0.001). The difference between two groups were also statistically significant (p<0.001). Padma et al conducted similar study in India found significant difference in Family Functioning between two groups (p<0.05) <sup>5,13</sup>.

## Conclusion

It can be concluded that the health-related quality of life and family functioning in parents of children with thalassaemia are lower score in all domain of HRQOL and family relationship. So proper counseling, emotional support and relaxation therapy etc. are recommended for parents having children with thalassaemia. However, our results should be interpreted in the light of small sample size and more studies with large sample sizes are required.

## References:

1. Ali S, Sabih, Jehan et al. psychological distress and coping strategies among parents Mumbai, India: Novert India.
2. Choudhury, V.P(2000). Thalassaemia : Care and control in the new millennium. Mumbai, India: Novert India
3. Erkan, E. 2020. Thalassaemia Syndromes: Junet L. Kwiatkowski, Nelson Textbook of paediatrics, 21sted, Elsevier, Philadelphia, PP. 2554-55
4. Brittenham GM, Griffith PM, et al. Efficacy of deferoxamine in preventing complications of iron overload in patients with thalassaemia major. *New Engl J Med.*1994;331(9):567-73
5. Bakthavatchalam P, P Vetriselvi. Assessment of quality of life among parents of children with thalassemia. *Int.J.Adv.Res.*2019;7(8):1074-1083
6. Deepak SS, Jay SP, et.al. Assessment of psychological impact on parents of thalassaemic children. *SAS J Med.*2017;4(3):57-60.
7. Hossain SM, Hasan MM, Petrou M, Telfer P, Mosabbir AA. The parental perspective of thalassaemia in Bangladesh: lack of knowledge, regret and barriers. *Orphanet J Rare Dis.*2021; 16:315
8. WHOQOL Group: The World Health Organization Quality of Life Assessment (WHOQOL) 1995, 'Position Paper from the World Health Organization, Special Issue on Health- Related Quality of Life: What Is It and How Should We Measure It?', *Social Science and Medicine*, vol.41, no.10, pp.1403-09
9. WHOQOL Group 1998. Development of the World Health Organization WHOQOL-BREF quality of life assessment. *Psychological Medicine*, vol.28, no.3, pp.551-558.
10. M Sachith, P Hashan, P Ravindu, B Dayananda, S de Udaya, M Chamila et al. Health related quality of life among children with transfusion dependent  $\beta$ -thalassaemia major and haemoglobin E $\beta$ - thalassaemia in Sri Lanka. *Health and Quality of Life Outcomes* (2019) 17:137
11. Sandra, J.S. (2015). Stress and Coping among Parents of Children Having Thalassemia. *International Journal of Science and Research*, Volume 4(7), 849-853.
12. Shaligram D, Girimaji SC, Chaturvedi SK. Quality of life issues in caregivers of youngsters with thalassemia. *Indian J Pediatr.*2007;74(3):275-78
13. Yamashita R, Sobota A, Trachtenberg F, Xu Y, Pakbaz Z et al. The impact of the child with thalassemia on the family: parental assessment by child Health Questionnaire. *Blood.*2009;114(22):1371.