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Quality of life in children aged 5- 14 years with beta thalessemia major

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ABSTRACT

Background: With recent advances for a chronic disease like thalassemia, where lifelong management is required, the quality of life, not just survival gains important. Owing to high burden of thalassemia in Odisha, this study analyses the quality of life in pediatric beta thalassemia major and the factors influencing the same.

Materials and Methods: This was a hospital based cross-sectional study done in a tertiary care hospital, Cuttack during September 2019 to January 2020. Children aged 5-14 years, diagnosed with beta-thalassemia major with regular blood transfusion, were subjected to modified SF-36 questionnaire to assess the quality of life in total and domains- General health , Physical health , Social activities , Limitation of activities, Educational , Psychological and Family aspect. Score above 50 considered as good. Data analysed using SPSS 18.0.Statistical significance was assessed by ANOVA and Chi-square test.

Results: Among 200 cases studied, majority (70.5%) had poor score, with mean being 49.19+6.53. In terms of domain, family aspect led (62.0+ 15.60), followed by limitation of activities(58.25+27.69), psychological aspect (51.75+ 12.47), physical health (50.85+14.60), educational aspect (41.92+ 19.294), general health (41.40+12.32) and social aspect was 38.17+ 24.20.

A significant association was noted between good quality of life and male gender (p-0.004), mother's occupation (p-0.013), number of children (p-0.001), higher serum ferritin level ($p<0.05$) and blood transfusion frequency (p-0.015) in the study population.

Conclusion: Considering the poor quality of life in children with thalassemia major, there is urgent need to focus on holistic approach towards management incorporating educational, emotional and physical rehabilitation, to ensure their productivity in the society.

1. Introduction

Thalassemia, the most common genetic disorder worldwide, is regarded as a serious problem in public health issues in the Mediterranean region, Southeast Asia, the Indian subcontinent and the Middle East.[1]

Thalassemia major, the most severe form, leads to severe anaemia and patients are in need of blood transfusion since the young age; present with failure to thrive, splenomegaly and complications of iron overload such as growth retardation and failure of sexual maturation.[2] Late complications are cardiac (dilated myocardiopathy and pericarditis), hepatic (chronic hepatitis, fibrosis, and cirrhosis), endocrinal (resulting in diabetes mellitus and parathyroid, thyroid, pituitary and less commonly adrenal

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glands insufficiencies) and hypersplenism.[3]

Nowadays, with improvement in the treatment of patients with thalassemia, these patients have a longer life expectancies and a larger number of them reach older ages.[4]

An increase in the life expectancy is accompanied by certain challenges such as bone diseases, infertility, consecutive referrals for blood transfusion, subcutaneous infusion of chelators, and moral stresses, which these aforementioned problems would affect mental, physical, social and educational functions of these patients.[1,5] Hence, authorities who provide services to patients should be aware of the related mental and social consequences in addition to the burden of this disease, just like any other chronic disease, to prepare better living environment for these patients.[6]

For a chronic disease such as thalassemia, where lifelong management is required, the quality of life, not just survival has become an important aspect for the provision of complete health care.[7]

The diagnosis and treatment of the thalassemia major could have an impact on family stability and family dynamics and bone deformities and short stature could induce poor self-image. Also, frequent hospital visits for transfusion, nightly subcutaneous infusions, delayed or absent sexual development and impaired fertility and complications such as heart disease, bone disease, diabetes, infections and Uncertainties about the future and difficulties in long-term planning could be mentioned as a result of thalassemia major.[8]

Previous studies done in other countries have shown the various struggles faced by thalassemia major patients in all physical, social and emotional domains, with poor levels of self-esteem and many limitations in normal day to day activities.[9–11] The factors responsible could range from their physical appearance, the burden of treatment modalities and complications of the disease.[12,13]

Odisha has a high burden of thalassaemic patients and yet not many studies have been done to assess their quality of life. Keeping this in mind, this study would attempt to analyse the quality of life in beta thalassemia major and the problems they face in their physical, social, personal and emotional life.

2. Materials and Methods

This study was a hospital based cross-sectional study done in a tertiary care hospital SCBMCH and SVPPGIP, Cuttack during the period of September 2019 to January 2020.

2.1. Inclusion criteria

1. Diagnosed case of beta thalassemia by High performance Liquid Chromatography (HPLC) or Hb electrophoresis.
2. On regular blood transfusion
3. Children aged between 5-14 years, indoor, outdoor and day care in SCBMCH and SVPPGIP, Cuttack.

2.2. Exclusion criteria

1. Presence of other hemoglobinopathies such as sickle cell, hbe, hbc
2. Presence of other chronic illness not attributed to thalassemia or its therapy.

3. Aims and Objectives

1. To measure the quality of life in patients with beta thalassemia major in terms of problems faced in their general, physical, educational, psychological and social life, and in total, using modified SF-36 questionnaire.
2. To assess the predictive factors associated with quality of life in these patients.

3.1. Collection of data

Data collecting tools consisted of two questionnaires: demographic questionnaire that included age, gender, body mass index, race, educational level, occupation, marital status, monthly income level, hospitalization record, and medication intake and; The thalassemia questionnaire applied to assess the patients' QOL. The thalassemia questionnaire about their quality of life is indigenously prepared, modified from SF-36 questionnaire and previously validated Thalassemia Qol questionnaire that was used in study in The Aga Khan University and Hospital (2014)[13]

Such a questionnaire assesses eight domains of QOL including General health (GH), Physical health (PH), Psychological Aspect (PH), Social activities (SA), Limitation of activities (LA), Educational and Family aspect. A maximum of 100 and a minimum of 0 is considered for each question. The scores considered for two-option, three-option & five option are (50 & 100), (0, 50 & 100), (0, 25, 50, 75 & 100) respectively.

The mean of total scores of all studied scopes will be calculated to measure the total score of individuals' quality of life. The mean of every scope will be calculated for every individual and, if the mean is lower than 50, the quality of related scope will be considered low and if it is higher than 50, it will be considered high.

3.2. Data analysis

All the data collected and compiled and analysed using SPSS 18.0 in the form of percentages. Statistical significance was assessed by ANOVA, Chi-square test and the Student paired t test, whenever appropriate. The level of significance was taken when p value < 0.05.

4. Results

Among the total of 200 thalassemia major patients aged between 5 years to 14 years enrolled in the study, the male to female ratio was 2:1 and majority (90%) were in the age group of 5 to 10 years. The demographic details including the socio-economic scale, occupation of the parents is reflected in Table 1. The patients were further assessed about their transfusion frequency and iron status as shown in Table 2. An attempt was made to assess for complications of iron overload in the thalassemic patients initially but later removed from the study, due to heterogeneity in the age at which complications are expected and, the variable follow-up and diagnostics opted by the parents to diagnose the same.

On assessment of the compliance and knowledge about the disease in a subjective manner, parents & attendants of 126(63%) felt they had good knowledge about the disease and 74(37%) were poor. Similarly, 158(79%) had good compliance to the treatment.

Using the modified SF-36 questionnaire, the quality of life of the thalassemia patients was assessed in total and separately in domains including General health (GH), Physical health (PH), Psychological Aspect (PH), Social activities (SA), Limitation of activities (LA), Educational and Family aspect. A score of 50 or more is considered as good quality of life.

Out of total 200 cases studied 141(70.5%) had quality of life total score less than 50 & 59(29.5%) had total quality of life score more than 50, which is considered good.(Figure 1) The mean of total scores of quality of life was 49.19+6.53. Likewise, in general health it was 41.40+12.32;that in physical health was 50.85+14.60;in psychological aspect was 51.75+ 12.47;in social aspect was 38.17+ 24.20;in limitation of activities was 58.25+27.69;in educational aspect was 41.92+ 19.294 and in family aspect was 62.0+ 15.60.

Various factors were considered which would possibly influence the quality of life in these children namely gender, parental income and occupation, socio-economic status, sibling status, transfusion dependence and knowledge about disease and compliance to treatment. Of these, a significant association was noted between good quality of life and male gender (p-0.004), mothers occupation (p-0.013), number of children (p-0.001), higher serum ferritin level ($p<0.05$) and blood transfusion frequency (p-0.015) in the study population.

Other factors were found to be statistically insignificant including socioeconomic status (p-0.399), father's occupation (p-0.54), age (p-0.42), HPLC status of the sibling (p-0.2), parental income (p-0.68), knowledge about the disease (p-0.29) and compliance to treatment (p-0.17).

Table 1: Demographic details of study population

Gender	**Percentage (n=200)**
Male	67
Female	33
Age (Years)	
5-10	90
11-14	10
Socioeconomic status	
Upper middle	3
Lower middle	46
Upper lower	50
Lower	1
Monthly income (RS/-)	
980-2935	3
2936-4893	28
4894-7322	42.5
7323-9787	19.5
9788-19574	5.5
>19575	1.5
Occupation of father	
Unemployed	0
Unskilled	18
Semiskilled	43
Skilled	33.5
Clerical	1.5
Semiprofessional	3
Professional	1
Occupation of mother	
Unemployed	91
Unskilled	1.5
Semiskilled	0.5
Skilled	1
Clerical	3.5
Semiprofessional	2.5
Professional	0
Sibling HPLC status	
Not applicable (Single child)	32.5
Not tested	36.5
Trait/diseased	21
Normal	10

Table 2: Transfusion and iron overload status in study population

Transfusion frequency (Per month)	**Percentage (n=200)**
Once	66
Twice	31.5
>Twice	2.5
Serum ferritin level	
0-1000	20.5
1001-2000	39.5
>2000	40

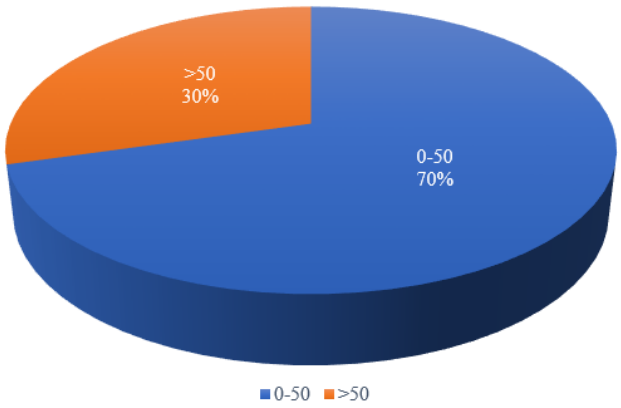

Figure 1: Quality of life score in study population

5. Discussion

With recent advances in treatment of thalassemia major, larger number of patients have longer life expectancy and survive till older ages than before. However, thalassemia being a chronic disease, patients despite survival, face many challenges, such as complications of disease, financial constraints and psychosocial challenges. In the long run, their quality of life gets compromised, at the cost of their disease. This study attempts to assess the quality of life in such patients, in total and in various domains.

In our study, out of 200 cases, 134(67%) were male & 66(33%) were female with male to female ratio being 2:1. Out of total 200 cases 180(90%) were of age between 5-10 years & 20(10%) were between 11-14 years.

Out of total 200 cases in our study, 41(20.5%) had ferritin level less than1000, 79(39.5%) between 1000-2000 and 80(40%) more than 2000. In the study done by Ansari et al,[14] *the* results were slightly different, with all the three groups having almost equal distribution of patients, around 33% each. On the other hand, a study done by Riaz et al in Pakistan,[15] most patients, (83.5%) had ferritin above 2000 and minimal number of patients (2.5%) had less than 1000. The difference between the studies could be due to the lack of regular follow-up in our study, and the non-availability of laboratory testing and specialist services in the peripheries, which led to higher number of patients in our study with higher ferritin levels.

Majority 132(66%) of the cases, in our study, had blood transfusion frequency once per month, 63(31.5%) twice per month and 5(2.5%) more than twice a month. The results of our study were consistent with that done by Ansari et al.[14] where most of the patients received blood transfusion once a month i.e. 67%. However, in the study done by Sezaneh et al,[16] where most patients i.e.53% were transfused twice a month. These differences in the transfusion frequency can be explained by the awareness among the parents to maintain a higher and optimum pre-transfusion haemoglobin level, which varies from place to place. It can further be influenced by the ease of accessibility of the hospital or blood transfusion facility.

Most patients in our study, 158(79%) had good compliance to the treatment and 42(21%) had poor compliance, which was similar to the studies done by Sezaneh et al[16] and Ismail et al.[17] Further, of the total 200 cases, parents & attendants of 126(63%) had good knowledge about the disease and 74(37%) had poor knowledge of the same. Similar results were obtained in study done in Karachi (59%)[18] and Saudi Arabia (64%) [19], which is because of high prevalence of thalassemia in their population as well.

Among our study population, 141(70.5%) had quality of life total score less than 50 & 59(29.5%) had total quality of life score more than 50, with mean score being 49.19. In other words, the overall quality of life in most children with Beta-thalassemia major was poor. This was consistent with various studies done in thalassaemic patients by Haghpanah et al.,[16] reported lower QoL scores in patients with thalassemia in Iran. Similarly, studies done in Greece[20] and Saudi Arabia[21] also reported a low quality of life among patients with thalassemia. In India, various studies done by Sharma et al,[22] Saha et al[23] and Chordiya et al[24] also reported lower level of quality of life in thalassemia patients, with the mean scores ranging between 36-48, which may be explained in terms of low education, standard of living, poor follow up, less access to quality health services and lack of awareness.

Our study revealed the mean of total scores of quality of life was 49.19+ 6.53.Likewise, in general health, it was 41.40+12.32, in physical health 50.58+ 14.606, in psychological aspect 51.75+12.47, in social aspect 38.17+ 24.20 which the lowest, in limitation of activities 58.25 +27.69, in educational aspect 41.92 + 19.29 and family aspect highest i.e. 62.0 + 15.60.

Various studies done by other authors, however, showed different domains to be affected to different extent. In a study done by Hakeem et al,[25] mean for physical aspect was the least i.e. 36.9 ±20.9 and for psychological was most i.e. 49.4 ± 17. The quality of life total score was 47.9± 38.8, which is comparable to our study. On the other hand, the study done by Yaghoob Madmoli[26] on quality of life in patients with â-thalassemia major in northern Khuzestan revealed the mean score in Limitation of activities was highest (72.60 ± 26.79) and the lowest in General health i.e. 58.47 ±21.37. The quality of life total score was 63.91 ± 19.45.Another study by Madmoli et al[27] showed similar results, where the total score in quality of life was 72.29+17.19. Thalassemic patients performed best with regards to domain - Limitation of activities (86.25 +17.49) and worst in General health (63.59+19.86). The results observed between our study and other studies varies according to the culture and social framework in each

place, and also the awareness about disease and treatment modalities available and how much they are followed. The highest score in our study was in the family aspect domain, which reflects the acceptance of disease by family members and strong family dynamics present in the region. However, the lowest scores in social aspect probably mean that though the disease is endemic in the region, there is still much social stigma expressed by people and discomfort by the patients themselves.

Among the various factors that were assessed to affect the quality of life in thalassemia, gender (p=0.004), occupation of mother (p=0.013), number of children (p=0.001), higher serum ferritin level (p<0.05) and frequency of blood transfusion (p=0.015) were found to be significant.

The total quality of life scores were higher among boys in our study as compared to girls and the difference was statistically significant (p- value=0.004). 54.5% of the boys in our study had score above 50 as compared to 33.3% of the girls. On the contrary, some studies done by Caocci et al.[28] and Saha et al.[23] have reported better scores for girls and other studies have shown no significant difference between boys and girls.[1,24,29] The lower scores in girls in our study may be due to poor attention given to girl child in our society, which may not be so in other countries.

The occupation of the mother of the thalassaemic child also played a role in determining the quality of life. In our study, most of the mothers were unemployed and better quality of life was seen with such patients. This is probably due to unemployed mothers spending most of their time at home with their children and thus being able to provide optimum care to their diseased children as compared to a working mother.

In the present study, frequency of blood transfusion and the total number of visits per year are predictors of physical and total quality of life scores and has inversely related to the total QoL scores. Children with transfusion once per month had better total QoL scores as compared to children visiting three times a month for transfusion. More frequent visits to the hospital have negative impact on children's lives in terms of physical burden, psychological burden and school attendance thus affecting the quality of life. This could be due to children having a constant stress of travelling all the way from long distances and being subjected to painful investigations and transfusion procedures. This finding was comparable to that reported Dhirar et al.[29]

A better quality of life was also observed in patients with lower serum ferritin values in our study, with p value being less than 0.05, which was comparable to the study done by Ansari et al.[14] All the patients in our study were on chelating agents (deferasirox/ deferiprone) and there was no difference in the quality of life, depending on the chelating agent used.

While studying association of knowledge about the disease and quality of life, p-value was found to be 0.11. Likewise, while studying the association of compliance towards treatment and quality of life, p-value was found to be 0.060.In other words, the quality of life showed no significant association with knowledge of the disease and the compliance to treatment. This was in contrast to the study done by Sezaneh et al[16], where a significant association was established between compliance to treatment and quality of life, though study done by Kaheni et al[30] also reported no significant association between the same. This difference could be due to the methods used to measure compliance in the different studies, ours being self-reported instead of using compliance tool.

The quality of life in children with thalassemia is poor, with certain domains such as social life, general health and education being more affected than others. Having physical impairments, social stresses, financial burdens and problems with their education and career make them very much vulnerable to psychological trauma early in their life. All of this creates a hindrance in their way of developing into autonomous functioning adults. There is, thus, great need for holistic approach involving physicians, government bodies, NGOs, parents-patients societies and corporate houses to come together and reduce the burden of thalassemia. Strategies to be taken into consideration to improve the quality of life of such patients, would involve education of the patients and family about the disease, establishing prenatal screening facilities, setting up more day care centres and special thalassemia clinics with multidisciplinary care in peripheries . There is also need to improve the existing schemes for these patients, in the form of new government policies, such as easy and affordable access to blood products in peripheries, subsidised medications and free laboratory check-ups, child and family counselling services, education catch up programmes in school and awareness programmes for the public, in order to reduce the stigma associated with thalassemia.

6. Conclusion

The quality of life in children with thalassemia major in Odisha is poor. Thus, there is urgent need to implement a holistic approach in their management protocols, which not only address the technical treatment of the disease, but also embibe measures to improve their educational, emotional and physical rehabilitation, such that they have a fulfilling and meaningful life, for themselves and society.

7. Conflict of Interest

None.

8. Source of Funding

None.

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