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Original Research Article

A Study to Compare Quality of Life of Healthy children and children with Thalassaemia

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Abstract: Thalassaemia is an increasingly serious public health problem especially in developing countries like India. The aim is to compare the quality of life of thalassemic patients with healthy children. This comparative study was conducted at paeditrics department of a teaching tertiary care hospital in Pune city. Quality of life of thalassemic patients was compared with healthy children by using PedsQL ™ Health-related quality of life (HRQOL) module. Statistical analysis: for descriptive data mean and standard deviation were used. Student two tailed t test was used as test of significance. Total 56 children were included in the study, out which 28 children were thalassemic patients and 28 were children were healthy. The mean age of the study participants was 6.018 years (SD=2.55 years). The scores of all four PedsQL domains (Physical, Emotional, Social and School functioning) of thalassemic patients were statistically significantly lower than those of the healthy children ($p < 0.001$). Among thalassemic patients there was no difference observed in gender-wise ($p > 0.05$). Quality of life of thalassemic patients was lower compared to quality of life of healthy children.

Keywords: Quality of life, Thalassemic patients, Healthy children, Comparision

INTRODUCTION:

Thalassaemia is a autosomal recessive hemoglobinopathy characterised 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]. Thalassaemia is an increasingly serious public health problem throughout the Mediterranean region, the Middle East, the Indian subcontinent and South East Asia [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].

The World Health Organization (WHO) defined the quality of life as: “An individual perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment [7].Some aspects of thalassemia major and its associated complications are expected to impact on the QOL. 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 [8,9].

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 [10]. We have observed in previous studies globally that the quality of life of thalassemic patients is severely impaired in various aspects. This study was conducted with the aim to compare the quality of life of

thalassemic patients using PedsQL™ Health-related quality of life (HRQOL) module with healthy children.

MATERIAL AND METHODS:

This comparative study was conducted in Paediatrics department of teaching tertiary care hospital in Pune city. The randomly selected diagnosed cases of beta thalassemia major receiving regular blood transfusions were included in the study. Diagnosis had been made according to their haemoglobin electrophoresis results.

The randomly selected healthy children who attended Paediatrics outpatient department for minor ailments were included after matching for demographic variables like age, gender, socio-economic class, education and occupation of parents of the children. The patients were assessed using PedsQL™ questionnaire given to all the parents of patients.

Research instrument:

The PedsQL™ Measurement Model is a modular approach to measuring health-related quality of life (HRQOL) in healthy children and adolescents and those with acute and chronic health conditions. The PedsQL™ Measurement Model integrates seamlessly both generic core scales and disease-specific modules into one measurement system. The details of the PedsQL™ Measurement Model may refered for references given [11-13].

STATISTICAL ANALYSIS:

The results obtained were tabulated in Microsoft excel sheet and the data was transferred to the SPSS 15.0 program for statistical analysis. Descriptive analysis was done for all data. Numerical data is expressed as mean, standard deviation 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 children were included in the study, out which 28 children were thalassemic patients and 28 were children were healthy. The mean age of the study participants was 6.018 years (SD=2.55 years) and they were ranging from 2 to 14 years. Of the total study subjects from these, 32(57.14%) were males, and 24 (42.85%) were females.

Total Quality of life scale score of the thalassemic patients was 70.84 (SD=11.31) and it was not significantly different between male and female thalassemic patients (74.28±10.63 vs 66.24±10.93, P=0.061). Total Quality of life scale score of the healthy children was 91.69 (SD=12.15). Total Quality of life scale score of the thalassemic patients was significantly lower than total Quality of life scale score of the healthy children (p< 0.05)

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

Sr. No.	Domain	Thalassemic patients	Healthy children	p value
1.	Physical functioning	61.74	90.45	<0.001, HS
2.	School functioning	75.25	92.86	<0.001, HS
3.	Social functioning	66.44	93.14	<0.001, HS
4.	Emotional functioning	79.71	92.58	<0.001, HS
5.	Physical summary score	73.88	92.86	<0.001, HS

*HS= Highly Significant

Table No. 1 listed mean scores of the four PedsQL 4.0 subscales and their Physical summary score, Psychosocial Health Summary (PCHS) for the thalassaemia patients and the differences of these scores compared to the healthy controls. The Physical summary score includes physical functioning scale average, PCHS is the average of the Emotional, Social and School Functioning, and the TSS is the average scores of all items. The scores of all four PedsQL domains (Physical, Emotional, Social and School functioning) are statistically significantly lower than those of the healthy control with p < 0.001. The summarised PCHS and Physical score was found to be statistically significant with p value< 0.001.

DISCUSSION:

This study was conducted in thalassemic patients attending Paediatric OPD of SKNMC and GH, Pune. Thalassemic patients appear well at birth but develop anaemia which progressively worsens due to partial or total absence of haemoglobin, if left untreated can result in early deaths [2, 3, 14-16]. The QOL of patients was assessed by using PedsQL 4.0 generic core scale. This core scale was chosen as it incorporates

various dimensions for measuring health related quality of life of paediatric populations. The effect of thalassemia on health related quality of life was found to be significantly impaired in comparison with healthy children. The use of this questionnaire in the assessment of thalassemia patients can help identify the impact of the disease and associated treatments [17]. It has been suggested that any measure of quality of life of children should include questions on physical, social and psychological functioning of a child.[18] Few studies suggest that the QOL of beta thalassemic patients has increased due to medical advances, improvement in therapeutic methods, safer blood transfusion, newer iron chelators and regular treatment methods [19, 20]. Other treatment like stem cell and bone marrow transplantation, gene therapy has been curative [21]. In this study we did not find any significant difference between male and female patients, but studies in the past suggest lower scores among females [22].

According to results obtained from this study, the physical functioning was more impaired than the other parameters. This study was conducted in a setting where the majority of patients belong to the lower socio-economic strata. Articles in the past have suggested that physical health can be affected by nutrition, external environment, family influences etc [23]. The results of this study suggested emotional functioning to be less impaired. In contrast, other studies suggested that emotional functioning is one of the most impaired domains in thalassemic patients [24]. Patients with chronic illnesses have their own coping strategies, hence the emotional functioning cannot be judged and could be one of the few factors leading to less significant difference [25]. There was a significant difference found between the physical summary score and the psychosocial summary score. The physical summary score was found to be on the lower side. The individual parameters of the psychosocial summary score, which included emotional, social and school functioning, had a variable outcome on comparison.

CONCLUSION:

This study concluded that quality of life of thalassemic patients is much lower than quality of life of the healthy patients. The lower scores in physical functioning domain could be due to the comorbidities and the disease related complication associated with Thalassemia. Prevention, proper management of disease related complications and greater knowledge among patients regarding the importance of co morbidity management and good compliance with iron chelating therapy as well as psychosocial financial support could be helpful in coping better with this condition.

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