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Quality of Life in Patients with Thalassemia Major

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Abstract: ***We conducted a case control study to compare the quality of life (QOL) in 50 children with thalassemia and 50 demographically matched healthy controls at a referral hospital in Northern India. Quality of life among children with thalassemia was significantly worse in emotional (P= 0.025) and school (P=0.011) functioning in self report and also in psychosocial (P=0.001), emotional (P=0.00), physical (P=0.03), social (P=0.00) functioning in parent proxy report. Factors [except age (P=0.000)] such as gender (P=0.951, socioeconomic status (P=0.593) and parent living status (P=0.478) did not significantly influence QOL scores.***

Keywords: thalassemia, quality of life, social, physical, demography

1. Introduction

Beta-thalassemia major (β -TM), also known as Cooley's anemia, is a hemoglobinopathy leading to chronic hemolytic anemia. If patients with β -TM are treated inadequately and inappropriately, it will be a fatal disease [1]. It is a common disease in Mediterranean countries, Southeast Asia, the Indian subcontinent and the Middle East [2,3].

The life expectancy and survival of these patients have increased dramatically over last decades through introduction of regular blood transfusion therapy and iron-chelating therapies [4]. Because of increased patients' survival, their quality of life (QoL) is believed to be lower than that of the normal population because of a variety of issues that these patients encounter during their lives, including the presence of co-morbid conditions, regular transfusions, infertility, disease complications, uncertainties about the future, psychiatric disorders, and difficulties in employment [5]. Because of these factors, patients with thalassemia experience many physical, psychological and social problems that lead to decreased QoL. 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" [6]. The present study was designed to assess the quality of life (QOL) among patients of thalassemia major.

2. Methods

A case control study was conducted from September 2014 to March 2016. Fifty thalassemic children aged 2-18 years attending Thalassemia clinic were included. Quality of life was assessed using Pediatric quality of life inventory (PedsQL^{TM} 4.0) [7]. The instrument was translated by professional translators in Hindi and was piloted on 10 parents prior to initiation of the study. It has two components: child self report (children> 5 years) and parent proxy report. The tool assesses the quality of life in five domains: physical functioning (8 items), psychosocial functioning (sum of emotional, social and school functioning), emotional functioning (5 items), social functioning (5 items) and school (5 items) functioning. The PedsQL scores range from 0 to 100 points with higher scores predicting better quality of life. Baseline demographic factors including age, gender and kuppuswamy's socioeconomic status of the family were collected [8]. The Mean QoL scores were compared among the cases and controls and also among various demographic variables using a unpaired t test and analysis of variance (ANOVA). All tests were two tailed and *P* value of less than 0.05 was considered statistically significant.

3. Results

A total of 50 patients of thalassemia major and 50 healthy controls participated in the study. Quality of life was lower in thalassemic group when compared with controls in all the domains although it was insignificant in physical, social and psychosocial domains of self report functioning and in school functioning domain of parent proxy report functioning.

Demographic factors including gender of children, parental socioeconomic status and parent living status did not significantly influence the total QOL scores among children with thalassemia whereas age significantly influence (p= 0.000) the quality of life.

4. Discussion

The present study highlights a lower quality of life in thalassemic children as compared to healthy controls. In addition, it was observed that demographic factors apart from age did not significantly affect the overall quality of life. We believe the study provides a further insight into this aspect of care of thalassemia affected children in the context of developing country. Our results for both univariate and multivariate analyses showed that age significantly influence the quality of life. Similar finding was observed by Ansari et al [9]. However, Shaligram [10] and Messina et al [11] didn't found any effect of age on QoL.

Thalassemia is one of chronic illness of childhood which not only affects physical well-being but also compromise emotional and social well-being. In addition, school dropouts and school absenteeism are perceived as a major handicap to care of chronic childhood illness like thalassemia in India. In the present study, performance on

emotional, social and psychosocial functioning as per parent proxy-report was significantly worse than those of healthy controls [Table 1].

Poor QoL in patients with thalassemia major is probably due to a complex combination of living with a chronic disease and new challenges related to improved life expectancy in thalassemia. It is important to bear in mind that QoL is a social construct influenced by cultural and contextual variables [12].

Although male gender and lower socioeconomic status contributed to almost two third of our enrolled cases, interestingly, our study did not find any significant influence of these factors on quality of life. In addition, parental living status also did not influence the overall quality of life in thalassemia in children. The lack of effect could be the result of small sample size, acknowledged as a limitation of the study.

To conclude, the present study shows overall quality of life in thalassemic children was worse when compared to healthy children and demographic factors except age did not affect the quality of life. However, studies with larger sample size could provide a further insight into factors affecting quality of life in children with thalassemia in India.

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Table 1: Quality of Life Scores in Cases and Controls

	Cases		Controls		P value
	N	Mean(SD QOL)	N	Mean(SD QOL)	
Self Report Functioning					
Physical		71.4 (33.5)		84 (32.3)	0.063
Emotional		66.5 (33.9)		81.5 (31.7)	**0.025**
Social		75.5 (36.9)		78.7 (31.4)	0.642
School		60.4 (35.4)		76.2 (24)	**0.011**
Psychosocial		67.8 (32.9)		78.8 (27.9)	0.067
Proxy Report Functioning					
Physical		84.5 (19.6)		94.2 (9.8)	**0.03**
Emotional		73.9 (15.4)		98.8 (3.6)	**0.00**
Social		76.3 (6.4)		86.5 (11.8)	**0.00**
School		67.6 (27.4)		74.8 (24.9)	0.167
Psychosocial		79.3 (11.2)		86.7 (10.9)	**0.001**
Total Score		75.2 (2.7)		84.9 (2.5)	**0.009**

Table 2: Factors Affecting Quality Of Life Among Cases

	Patients (N=50)	P value
Age (in years)		
2-4	84.3 (27.6)	**0.000**
5-7	66.8 (6.2)	
8-12	77.1 (18.8)	
13-18	83.3 (7.8)	
Sex		
Male	75.2 (21)	0.951
Female	74.9 (13.8)	
Socioeconomic status		
Upper	75.2 (35.1)	0.593
Upper lower	70.8 (11.8)	
Upper	77.9 (16.4)	
Upper lower	71.6 (19.2)	
Upper	64.7 (33.3)	
Parents living status		
Both alive	75.3 (19.6)	0.478
One expired	81.8 (4.7)	
Both expired	54.3 (-)	