



## Student Article

## Quality of life in transfusion-dependent thalassemia patients



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Received 15 October 2016; revised 6 May 2017; accepted 7 May 2017; Available online 17 June 2017

### المخلص

**أهداف البحث:** يُعد مرض الثلاسيميا أكثر الاضطرابات الوراثية شيوعاً في منطقة البحر الأبيض المتوسط. وعلى الرغم من التطورات الأخيرة في علاج مرض الثلاسيميا، فإن سكان البلدان النامية لا يحصلون على العلاج المناسب. وبالنسبة لمثل هذه الأمراض المزمنة فليس المهم فقط هو البقاء على قيد الحياة، ولكن أيضاً جودة الحياة، التي تقودها في المقام الأول القيود النفسية والاجتماعية. تستكشف هذه الدراسة عوامل مختلفة تؤثر على جودة الحياة عند مرضى الثلاسيميا المعتمدين على نقل الدم.

**طرق البحث:** شملت هذه الدراسة المقارنة، أطفالاً يعانون من الثلاسيميا الكبرى ويتلقون نقلاً منتظماً للدم للسنوات الخمس الماضية. وتمت مطابقة الضوابط بالنسبة للعمر، والجنس، والوضع الاقتصادي الاجتماعي، وكانت الضوابط أطفالاً أصحاء فقط. تم تقييم أنواع مختلفة من "جودة الحياة" باستخدام أداة تقييم جودة الحياة لمنظمة الصحة العالمية.

**النتائج:** شملت دراستنا 90 حالة مصابة (8 حالات تسرب) و98 من الضوابط (بلا تسرب)، بعمر 8.3 ± 4.4 في الحالات المصابة و12.2 ± 4.7 في الضوابط. ومجموع متوسط النتيجة الكلية لجميع الأسئلة بالنسبة للمصابين كان 82.04 ± 15.54، بينما كانت 87.86 ± 12.9 في الضوابط. وكانت الفوارق بين المصابين والضوابط أكثر وضوحاً في الذكور في كل العوامل تقريباً. ولم تكن هناك فوارق ذات قيمة بين المجموعتين بالنسبة لمتغيرات الألم، والمظهر، والعلاقات مع الآخرين.

**الاستنتاجات:** على الرغم من عدم وجود فرق كبير في درجة جودة الحياة عند أطفال الثلاسيميا، إلا أننا وجدنا فارقاً كبيراً بين الذكور مقارنة بالإناث. وتتطلب مؤشرات هذه النتيجة أن تُطرق في دراسات مقارنة أخرى.

**الكلمات المفتاحية:** أطفال؛ جودة الحياة؛ الثلاسيميا الكبرى؛ عوامل نفسية؛ ألم جسدي

### Abstract

**Objectives:** Thalassemia is the most common genetic disorder in the Mediterranean region. Despite recent advances in the management of thalassemia, people living in developing countries do not receive satisfactory treatment. For such chronic conditions, not only is patients' survival important but their quality of life (QOL) is also important, which is primarily driven by psychological and social constraints. This study explores various factors that affect QOL in transfusion-dependent thalassemia patients.

**Methods:** This case control study included children with thalassemia major who received regular transfusions for the last five years. Controls were matched for age, gender and socio-economic status and included only healthy children. Different types of QOL were assessed using the World Health Organization (WHO) Quality of Life Assessment tool.

**Results:** Our study included 90 cases (8 dropouts) and 98 controls (0 dropouts), with an average age of 8.3 ± 4.4 in cases and 12.2 ± 4.7 in the control group. The total mean aggregate score of all patient questions was 82.04 ± 15.54; in the control group, the score was 87.86 ± 12.9. In nearly all factors, differences between cases and controls were most significant in males. There were no significant differences for the variables of physical pain, appearance and relations with others in both groups.

**Conclusion:** Although there was no significant difference in the QOL score in thalassemia children, a more significant difference was observed in male patients than in females. The implications of this finding must be explored in further case-control studies.

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Peer review under responsibility of Taibah University.



**Keywords:** Children; Physical pain; Psychological factors; Quality of life; Thalassemia major

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## Introduction

Worldwide, thalassemia is a serious public health problem because of the high prevalence extending from the Mediterranean and parts of Africa throughout the Middle East and the Indian sub-continent, Southeast Asia, Melanesia and into the Pacific Islands, ranging from 2% to 25%.<sup>1–3</sup> Each year, 50,000 to 100,000 children die of thalassemia major in low- and middle-income countries, and approximately 7% of the world's population are carriers of a haemoglobin disorder.<sup>4,5</sup>

Despite recent advances in thalassemia management, people living in developing countries do not receive satisfactory treatment.<sup>6</sup> For such chronic conditions, not only patient survival is important but also their quality of life; psychological and social functioning are particular constraints.<sup>7–10</sup> The complications of thalassemia major are known to affect quality of life.<sup>11</sup> According to the WHO definition, quality of life (QOL) is individuals' perceptions 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.<sup>12</sup>

Beta thalassemia major is the most severe form of thalassemia, characterized by a severe microcytic, hypochromic iron deficiency.<sup>8</sup> In paediatrics particularly,  $\beta$ -thalassemia major and its complications are associated with noteworthy psychological effects, emotional burdens, hopelessness, and trouble with social integration. Children with thalassemia demonstrate weakened abstract thinking and difficulties with language, consideration, memory, constructional/visual spatial abilities, and executive functions, all of which are more prominent in haemosiderotic subjects.<sup>13,14</sup> These

children feel slightly different from their peers and develop negative thinking about life, show more anxiety and possess low self-esteem. Although their behavioural profile is similar to normal people's, a large number of these children demonstrate severe psychological deficits because of trouble following agonizing chelation.<sup>15–18</sup>

## Goal

The purpose of the study is to access the quality of life of transfusion-dependent thalassemia patients in the paediatric age group.

## Materials and Methods

This case control study selected 98 children (cases) having thalassemia major who were receiving regular transfusions (once every 4–6 weeks minimum) for the last five years; 98 healthy controls from the schools were matched for age, gender and socio-economic status. Written informed consent was obtained from the parents of all participants younger than 18. Quality of life was assessed using the standardised tool WHO-QOL-BRF (Arabic Version) and was conducted in a tertiary care hospital, King Saud Medical City, Riyadh, KSA from March 2016 to February 2017. Ethical approval was granted by the Institutional Review Board under IRB registration number H-01-R-053.

From the total sample of 196 children, we eliminated the records of 8 cases because of inappropriate responses or because participants declined to respond properly after consent was granted. Hence, we had data from 188 records, analysed using SPSS 21.0, and the results are presented as descriptive and inferential statistics using Chi-square and *t*-test for scores of QOL BRF with a 5% level and tested for statistical significance.

## Results

The average age in the control group was  $12.2 \pm 4.7$  years and that of the case group was  $10.3 \pm 4.4$  years. We observed that a majority (73.9) of the children had 'good' and 'very

**Table 1: Domain 1: Response to physical health domain.**

	Status		p-Value	Status		p-Value	Status		p-Value
	Case	Control		Case	Control		Case	Control	
<b>Physical Pain</b>									
Not at all	9	44	0.000	3	1	0	3	3	0.765
A little	21	32		23	7		5	7	
A moderate amount	28	16		26	26		27	28	
Very much	21	2		33	38		37	40	
An extreme amount	8	2		4	23		16	20	
<b>General Health</b>									
Very dissatisfied	3	2	0.000	1	0	0.000	2	5	0.001
Dissatisfied	18	7		13	3		20	7	
Neither satisfied nor dissatisfied	22	16		32	21		21	16	
Satisfied	40	44		35	42		38	40	
Very satisfied	5	28		8	27		8	29	

\*Statistically significant at 0.05.

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