HEALTH-RELATED QUALITY OF LIFE IN SICKLE CELL DISEASE PATIENTS IN AKRE, IRAQI KURDISTAN

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ABSTRACT

Background: Sickle cell disease is an important health problem in Akre- Iraqi Kurdistan, and this study aimed to assess health-related quality of life (HRQoL) in this condition.

Patients and Methods: A total of 63 patients registered as sickle cell disease at Akre thalassemia center in Kurdistan, and an equivalent number of age and sex matched healthy individuals, were recruited. The patient records were retrieved and their clinical and laboratory findings reviewed. Children and adolescent had their HRQoL assessed using PedsQL 4.0 generic score, while the Medical outcome study 36 item short form (SF-36) was used for adults.

Results: The mean age ± SD of the enrolled patients was 15.43 ± 8.79 years, and included 44 females and 19 males. The overall mean HRQoL in both children and adults were significantly worse than respective healthy counterparts, and adults fared worse than children. Among the predictors of low quality life were the occurrence of painful episodes, transfusion frequency, S. Ferritin ≥ 2500 ng/ml , LDH ≥ 700 U/L, and avascular necrosis of femoral head (P= 0.02 , 0.007 , 0.012 , 0.025 and 0.002 respectively).

Conclusions: Both children and adults with sickle cell disease at Akre thalassemia center had worse quality of life compared to their healthy counterparts. Several predictors for a worse HRQoL were identified, in the studied cohort. Further studies from other centers are necessary to have a more comprehensive view of the HRQoL in Iraqi Kurdistan.

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Keywords: Health-related Quality of Life, HRQoL, Iraq, Sickle cell disease, SF-36, PedsQL.

Sickle cell disease (SCD) is an inherited autosomal recessive hemoglobin disorder due to the substitution of valine for glutamic acid at position 6 of β-globin chain of hemoglobin, which leads to the formation of hemoglobin S. Hemoglobin S polymerizes upon de-oxygenation leading to a phenotype characterized by chronic hemolytic process, often accentuated by a variety of crises particularly vaso-occlusive ones, culminating in multi-organ damage[1]; In addition to its effects on physical functioning, SCD also exerts social, psychological, emotional, and academic impact on the life of the affected individual[2].

Over the past few decades, the concept of health-related quality of life (HRQoL) and its assessment gained wide popularity,

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since it measures the patient's perception of the effect of the illness on his/her wellbeing and ability to function in several domains including physical, mental and social domains of life[3].

There are numerous HRQoL instruments, the most common generic tool that has been used in children with chronic diseases is the 23 item PedsQL generic core scale, which include a parent-proxy and child self-report versions.[4] In adults, on the other hand, the Medical outcome study 36 item short form [RAND 36 (SF-36)] is the most popular generic instrument used[3,5-7].

To our knowledge there are no studies addressing the HRQoL in Iraqi Kurds with SCD, and because of the importance of this assessment and its possible impact on patients' management and wellbeing, the current study was initiated aiming at assessing the HRQoL in SCD, and at determining the predictors associated with lower HRQoL in a single center in Akre, Kurdistan, Iraq.

PATIENTS AND METHODS

This study was conducted at the thalassemia center in Akre –Kurdistan, Iraq during the period between May 2018 and August 2018.

All 67 registered patients with the diagnosis of sickle cell disease at the center were approached and recalled. A total of 63 consented to participate in the study. The patients had their original diagnoses reconfirmed by hematological and/or molecular studies as required. The patients included 41 children and adolescents (5-17 years old) and 22 adults (18-40 years old). They included 19 males and 44 females. Additionally, sixty-three apparently healthy individuals from the same locality, who are age and sex matched with the patients, were assigned as a control or comparison group.

All patients had their records reviewed and had a detailed history and clinical examination, full blood counts by a hematology analyzer (Sysmex XP300-USA), reticulocyte count, serum lactic dehydrogenase, S. Ferritin, sickling test by routine laboratory procedures, and high performance liquid chromatography using Beta short program on Bio-Rad D-10 instrument (Bio-Rad, CA, USA).

For children the HRQoL was assessed using the Pediatric Quality of Life Inventory™ (PedsQL™) 4.0 Generic Core Scale-Kurdish language version,[4] after the completion of the relevant user agreement form. The Kurdish translation was prepared earlier and linguistically validated and approved by the owner Dr James Varni (Mapi Research Trust-France)[8]. Based on the latter study, this Kurdish version was found to have a Cronbach's alpha reliability for internal consistency of 0.88 and 0.87 for overall score in child and parent proxy reports respectively[8], which is considered quite acceptable. PedsQL generic score scale consists of 23 items which could be used for healthy, acutely and chronically ill children and adolescents. The scoring process has been detailed elsewhere[4], though in summary: a five-point scoring system is used, where 0 denotes no problem, while 4 almost always a problem. These items are arranged in four domains, eight in physical, and five in each of emotional, social and school functioning. The outcome is a total score in each of the four domains and an overall mean score. Each scale is reverse scored from 0-100,

with the higher values indicating better life quality.[4]

For adults the RAND-36 (SF36) questionnaire was applied to evaluate the impact of the disease on these patients. SF36 is multidimensional questionnaire with 36 items divided into 8 domains: 10 items for physical functioning, 5 items each for emotional well-being and general health, 4 items each for role limitation due to physical health and energy fatigue, 3 items for role limitation due to emotional problem, 2 items each for social functioning and pain. The resultant scores ranges from 0 to 100, where higher figures represent better quality of life[3,9]. The scoring process is a rather lengthy two-step process which has been detailed elsewhere6.The forms, whether for adults or children, were self-reported, except in those < 8years old, or if the participant was illiterate.

All statistical analyses were performed using SPSS software (SPSS Inc, Chicago, IL, USA). Two tailed independent t-test and Pearson correlation were used, as required. P-value < 0.05 was considered significant.

The study was approved by the ethics committee at the Kurdistan board of medical specialties and directorate of health in Duhok, Iraq. Informed verbal consent was obtained from all enrollees or their guardians.

RESULTS

The current study included 63 patients with a mean age of 15.43 (SD 8.79) years, and comprised 44 females and 19 males. The study group included 41 children and 22 adults. In addition, 63 age and sex matched healthy individuals who had a mean age of 15.3 (SD 8.68) were concomitantly recruited.

Table (1) and (2) outline the main clinical and laboratory features of the 63 patients at the time of enrollment as well the cumulative disease specific complications.

For children the overall mean HRQoL score was found to be 62.8% (SD 21.15). The lowest scores for the domains examined was for physical health at 42.89% (SD 30.65), while the highest was for social functioning at 76.46 % (SD 15.01). When patients were compared to their healthy counterparts, there were significant differences between the overall mean score, as well as all domains except for emotional functioning (Table 3A). There were no significant differences in HRQoL between male and female patients, whether in overall scores or scores in each domain (p>0.05 in all). Moreover, Pearson correlation demonstrated that the overall mean scores were significantly correlated between child's report and parent proxy reports (r = 0.75; p < 0.001) [Figure 1].

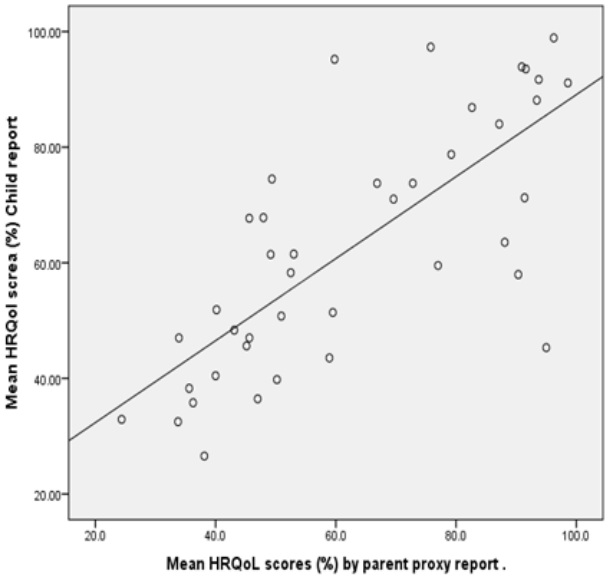

Figure1: Correlation between Mean HRQoL Scores in Child and Parent-Proxy Reports.

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Table 1: The Main Clinical Features of the 63 Enrolled Patients.

Clinical features	Patients' no. (%)
Age	
< 18 years	41(65.1)
≥18 years	22(34.9)
Gender	
Females	44 (69.8)
Males	19 (30.2)
Painful episodes requiring admission/year	
0	52 (82.54)
1	7 (11.11)
2 - 3	3 (4.76)
>3	1 (1.59)
Blood transfusion/year	
0	31 (49.2)
1	9 (14.29)
2 – 3	7 (11.11)
>3	16 (25.4)
Chelation therapy	
Yes	13 (20.63)
No	50 (79.37)
Hepatomegaly	
Yes	12 (19.05)
No	51 (80.95)
Splenomegaly / Splenectomy	
Yes	33 (52.38)
No	30 (47.62)
Gall stone / Cholecystectomy	
Yes	16 (25.4)
No	47 (74.6)
Life time cumulative incidence of specific complication	
Stroke	0 (0)
Avascular necrosis	5 (7.94)
Acute Chest Syndrome	1 (1.59)
Aplastic crisis	1 (1.59)
Priapism	0 (0)
Leg ulcer	1 (1.59)
Socioeconomic status	
Low income	34 (54)
Middle/high income	29 (46)

Table 2: The Main Laboratory Parameters among 63 SCD Patients Enrolled.

Laboratory Features	Patients no. (%)
Hemoglobin	
≥ 9 g/dl	23 (36.51)
≥ 8 - < 9 g/dl	21 (33.33)
6 - < 8g/dl	16 (25.4)
< 6 g/dl	3 (4.76)
Leucocyte count	
< 11,000 mm^3	37 (58.73)
11,000 – 15,000 mm^3	14 (22.22)
>15,000 mm^3	12 (19.05)
Reticulocyte count	
< 5%	7 (11.11)
6 – 10%	17 (26.98)
11 – 15 %	15 (23.81)
≥16%	24 (38.1)
HbF%	
< 5%	16 (25.4)
5 – 10%	20 (31.75)
10.1 – 14.9%	19 (30.15)
≥15%	8 (12.7)
L.D.H. (on 57 case).	
< 700 U/L	48 (84.2)
≥ 700 U/L	9 (15.8)
S.Ferritin (on 62 case).	
Female ≤ 250 ng/ml	20 (32.26)
Female > 250 ng/ml	23 (37.1)
Male ≤ 350 ng/ml	5 (8.06)
Male > 350 ng/ml	14 (22.58)
Overall < 2500 ng/ml	50 (80.65)
Overall ≥ 2500 ng/ml	12 (19.35)
HCV. antibody	
Yes	5 (7.94)
No	58 (92.06)
HbS Antigen	
Yes	0 (0)
No	63 (100)

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For adult patients the overall mean HRQoL was found to be 46.17% (SD 27.95). The lowest score was for role limitation due to physical health at 29.55% (SD 43.39), while the highest was for emotional well-being at 58.27% (SD 22.81). The overall mean scores were significantly lower among adult patients compared to their healthy counterparts, which was due to significantly lower scores in all domains (All with P<0.001) [Table 3B]. While there were no significant difference between males and females in adult patients' group overall and within each domain. Furthermore, the overall HRQoL mean in adults was significantly lower than that of children (p=0.02).

Table (3A): HRQoL and Age Comparison between Patients with Sickle Cell Disease and their Healthy Counterparts (Age 5-17 Years).

Category	HRQoL Scores (Mean ± SD.)				
	Physical	Emotional	Social	School	Mean
Patients	42.89±30.65	63.66±24.4	76.46±15.01	69.63±20.7	62.8±21.15
Controls	78.44±13.95	71.1±21.3	88.78±12.08	79.75±15.76	79.11±12.44
P-value	<0.001	0.145	<0.001	0.027	<0.001

Table (3B): HRQoL Comparison between Adult patients with Sickle Cell Disease and their Healthy Counterparts (ages 18–40 years).

Category	HRQoL Scores (Mean ± SD)								
	Physical functioning	Role-Physical	Role-Emotional	Energy-Fatigue	Social functioning	Pain	General health	Emotional well-being	Mean
Patients	52.5± 30.22	29.55±43.39	36.36±49.23	50.91±25.43	55.34±29.4	44.89±33.98	41.73±21.14	58.27± 22.81	46.17± 27.95
Controls	80.23±14.01	78.41±19.35	82.57±16.65	77.27±11.31	90.34±18.87	86.14±14.26	79.55±9.24	82.73± 10.64	82.15± 8.87
P-value	<0.001	<0.001	<0.001	<0.001	<0.001	<0.001	<0.001	<0.001	<0.001

Table 4 shows HRQoL overall mean and its relevance to some clinical and laboratory parameters for all 63 patients. It was documented that those with at least one painful episodes, S. Ferritin ≥ 2500 ng/ml, S. LDH ≥ 700 U/ml and 3 or more blood transfusion/year, had significantly lower mean HRQoL scores when compared to those with no such events.

Though Hb < 9 g/dl, reticulocyte count >10% , and Hb F < 10% were associated with lower mean HRQoL scores, however none were statistically significant. Moreover, table 4 also shows that those with low socioeconomic status had lower mean HRQoL when compared to those with middle/high status, though this was not statistically significant.

Table (4) Mean of HRQoL and its Relevance to some Clinical and Laboratory Parameters.

Parameters		HRQoL of overall patients (Mean ± SD.)
Painful episodes requiring admission /12 months		
	No	63.18 ± 23.47
	Yes	48.74 ± 24.62
P-value		0.02
Transfusion frequency /12 months		
	< 3	61.56 ± 26.78
	≥ 3	46.42 ± 15.58
P-value		0.007
S.Ferritin		
	< 2500 ng/ml	61.18 ± 25.24
	≥ 2500 ng/ml	44.36 ± 18.91
P-value		0.012
Hemoglobin.		
	≥ 9 gm/dl	59.13 ± 28.62
	< 9 gm/dl	55.68 ± 22.5
P-value		0.5
Leucocyte count.		
	< 11,000 / mm^3	55.47 ± 25.6
	≥ 11,000 / mm^3	59.16 ± 24.03
P-value		0.5
Retic. Count		
	< 10%	59.94 ± 26.9
	≥ 10%	55.62 ± 24.03
P-value		0.5
L.D.H.		
	< 700 U/L	60.19 ± 26.76
	≥ 700 U/L	47.21 ± 11.65
P-value		0.025
Hb F%		
	< 10%	54.04 ± 25.96
	≥ 10%	60.78 ± 24.53
P-value		0.327
Avascular necrosis femoral head		
	No	59.83 ± 23.62
	Yes	24.18 ± 12.43
P-value		0.002
Socioeconomic status		
	Low	53.04 ± 25.17
	Middle income/Effluent	61.63 ± 24.06
P-value		0.173

On the other hand, except for avascular necrosis (AVN) of femoral head seen in 5/63 patients, all other cumulative events/crises were sporadic or absent among enrollees. AVN was found to be significantly associated with much lower quality of life (p=0.002)

DISCUSSION

The measurement of the health-related quality of life in sickle cell disease has emerged as a valuable tool to assess the patient's perspective of their disease, and aid the attending physicians when considering various available management options as well as in predicting possible outcomes[5,10]. Multiple tools for assessing

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HRQoL have been introduced over the years, however PedsQL 4.0 generic tool for children and SF-36 for adults have gained popularity because of their reliability, validity and reproducibility[3,5,11-14].

The main finding of this study was that patients with SCD from Akre, had significantly lower health related quality of life compared to their healthy counterparts, whether children or adults. This is consistent with the bulk of the literature on children[5,9,10,12,15-17], and on adults[18-22] .

The most important contributor to the lower overall mean HRQoL in children was reduction in physical functioning domain, which is similar to that reported in other SCD populations like Southern Iraqis, American blacks, Tanzanians, and Brazilians[9,23-25]. While the main contributor to lower overall mean HRQoL in adults was reduction in role physical, which is also consistent with studies on Saudi Arabian and African American patients, which showed that this domain is either the worst or among the worst affected[18-20,26].

An important observation of the current study is that the overall mean HRQoL was much lower in adults than children, which is going with notion that with advancing age there is increasing organ damage and morbidity, thus a worse quality of life. This is consistent with observations from African Americans and Saudi Arabian SCD patients[15,18,20].

Among the predictors identified in association with worse HRQoL in the current study is the occurrence of pain crises, which was also well documented by many studies worldwide in both children and adults [9,17,21,26-30]. Another identified predictor of worse HRQoL is transfusion frequency, again noted by several earlier studies worldwide[19,31]. The latter, as well as higher S. Ferritin, LDH and reticulocytes, lower Hb and HbF%, are actually associated with more severe disease and thus higher rates of hemolysis and more transfusions, and eventually more organ damage and worse quality of life. Though it should be noted that though all these five parameters were associated with lower mean HRQoL, however this was significant in the first two only. This could probably be explained by the limitation of the number of registered SCD patients that were available at the center.

The scarcity of the cumulative events related to SCD in the current cohort, may be related to the moderate severity of the SCD in this locality[32], but may be also due to the fact that some events were not documented in the patients' records and despite the best efforts of the researchers may have been missed due to illiteracy of most the patients and their parents. However, it has been noted by earlier studies, that it is the pain episodes and socioeconomic status that is likely to be related to HRQoL and not the cumulative events relevant to the disease[30], with the exception of AVN as documented by at least one study and as shown in our own observations[18].

In conclusion, it appears that HRQoL in both children and adults with SCD in Akre thalassemia center is worse than their healthy counterparts. Furthermore, it appears that the main predictors of HRQoL are the occurrence of pain episodes, more frequent transfusions and higher serum Ferritin and LDH. Studies including SCD

patients in other centers in the Kurdistan region are warranted.

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ثوختة

جورىَ ذيانا طريَدايى ب ساخلةميىَ ظة ل دةظ نةخوشيَن خانةييَن شالوكى ل ئاكرىَ، كوردستانا عيراقىَ

ثيَشةكى: كيَم خوينى منجلي طرفتةكا تةندرستييا طرنكة ل دةظةرا ئاكريَ ئةظ خويَند نة ئارمانجة بؤ هةلسنطاندنا ذيانةكا باش.

نةخوَشان و ريَك: ئةظ خوَيَند نة ل سةر حالةتيَن و ديتنيَن ثيَك هاتية ل سةر 63 نةخوشان ب نةخوشييا كيَم خوينى منجلي هاتينة تؤماركرن ل سةنتةرا (الثلاسيميا) ل ئاكريَ / كوردستان دطةل وان كةسيَن وةكي وان ب تةمةني و رة كةزي ييَن ساخلةم و ثيَشتي ظةطةريانا ثةرتووكيَن نةخوشان و ديتنا ئةنجاميَن تةختي و تاقيطةهيَن ، ذيانا زاروكيَن نةخوَش هاتة هةلسةنطاندن بـPedsQL ، و ذيان مروظيَن مةزن هاتة هةلسةنطاندن بـSF36.

ئةنجام: ناظنجييا ± خوارى ثيظةر بؤ نةخوَ شيَن هاتينة تؤماركرن (15,43±8,79) كو 44ذن و 19زةلام. ناظنجييا طشتي بؤ ثاشيا ذيانيَ بؤ زاروكان و مةزنان ئاشكرا بؤ كة ذيانا وان خراثترة ذ ذيان زاروكان و مةزنان ئةويَن ساخلةم، و ذيان مروظيَن مةزن خراثتر بوو ل زاروكان. و ذوان خاليَن ئةويَن ئاشكراد كةن ب باشيا ذيانا نزم ئةظةنة: ضيَبينا نةوبيَن ئيَشانيَ، ظةطوهاستنا خوَيَنا دووبارة، ثشكنينا زانينا ئاسني ≥ 2500 نانوغرام/ ملم، انزيم ذيفةكرنا هايدروجينى لاكتاتى ≥ 700 يةكيَن دةولةت/ ليتر و زفربونا جوما لسةر هيَستكيَ راني (بهايىَ P = 0،02 / 0,007 /0,012 / 0,025 / 0,002 لسةر يةكي).

ديتن: هةمي زاروك و مةزن ييَن نةخوَشيا كيَم خويني منجلي هةين هاتينة تومار كرن ل سةنتةرا ثلاسيميا ل ئاكريَ ذيانا وان خراثترة ل وان كةسيَن ساخلةم، زوَر خال د ظيَ خوَيَند نيَ دا هةين كة ذيانا مروظيَن (كيَم خوَينا منجلي) هةين خراثترة ذ ذيانا مروظيَن ساخلةم 0 زوَر طرنكة كة خوَيَندنيَن زياتر بهيَنة كرن ل سةنتةريَن دي دا بطةهينة ئةنجاميَن باش و طشتي لسةر ذيانةكا باش ئةويَن ثةيوةندي هةبيت ب تةندروستييَن ذظيَ دةظة ريَ .

الخلاصة

نوعية الحياة المتعلقة بالصحة في مرضى الخلايا المنجلية في عقره ، كردستان العراق

الهدف: فقر الدم المنجلي هي مشكلة صحية مهمة في منطقة عقرة , وهذه الدراسة تهدف الى تقييم جودة الحياة في هذه الحالة.

المرضى والطرق: تم دراسة مجموع 63 مريض بفقر الدم المنجلي تم تسجيلهم في مركز الثلاسيميا بعقرة/ كوردستان مع ما يماثلهم في العمر والجنس من الأصحاء. وتم أسترجاع سجلات المرضى وأستعراض النتائج السريرية والمختبرية. الأطفال والمراهقين تم تقييم جودة حياتهم بأستخدام الاستبيان الخاص بجودة الحياة للأطفال (PedsQL) بينما للمرضى البالغين تم أستخدام الأستبيان الخاص بالبالغين (SF36).

النتائج: المتوسط ± الأنحراف المعياري للمرضى المسجلين كان (15.43 ± 8.79) ويشمل 44 أنثى و19 ذكر. وقد وجد ان المتوسط العام لجودة الحياة في كلا الأطفال والبالغين كان بشكل واضح أسوء من نظرائهم الأصحاء، والبالغين كانوا أسوء حالا من الأطفال. كان من بين النقاط المنبئة بجودة حياة منخفضة هو حدوث نوبات ألم، نقل الدم المتكرر، S. Ferritin ≥ 2500 نانوغرام/ ملم، LDH ≥ 700 وحدة دولية/ لتر والنخر اللاوعائي لرأس عظم الفخذ (P =0.02/ 0.007/ 0.012/ 0.025 و0.002 على التوالي).

الاستنتاجات: وجد أن كلا من الأطفال والبالغين المصابين بمرض فقر الدم المنجلي المسجلين في مركز الثلاسيميا بعقرة لديهم جودة حياة أسوأ من نظرائهم الأصحاء. وقد حددت عدة نقاط تتنبأ بجودة حياة أسوأ حددت في هذه الدراسة. من الضروري إجراء مزيد من الدراسات في المراكز الأخرى للحصول على رؤية أكثر شمولا لجودة الحياة المتعلقة بالصحة في هذه المنطقة.

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