



Basra Center for Hereditary Pediatric Blood Diseases, Patient Characteristics and Attitudes

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Received 19 November 2023;

Accepted 28 December 2023;

Published 06 January 2024

Abstract

Background thalassemia and sickle cell diseases are highly prevalent in our locality and in Basrah governorate, Basrah center for pediatric hereditary blood disease is one of the biggest centers in Iraq with a large cohort of heterogeneous patient groups registered, services, patient demography and attitudes all were preliminarily expressed in this study in a descriptive way. **Method** cross-sectional descriptive study expressed general data and data from direct inquiry of selected sample regarding their QOL, satisfaction and complications. **Results** Basrah center involves patients most of whom are of SCD and thalassemia, sample selected showed that family breakage or social breakage was not evident in (79.5%), a general QOL scoring most of the studied sample specified fair score in (63.4%), (82.20%) were generally satisfied regarding their general health, 95.50% were satisfied with collective fair and satisfied score in regard of acceptance of their general appearance, (27.7%) did agree that physical pain is affecting their life, (24.1%) were dissatisfied regarding general health system while 58% showed collective of fair and satisfied score, (63.4%), (61.6%) were satisfied regarding medical staff management were 34.8% showed dissatisfaction, accessibility to medical service was dissatisfied in (42.9%) most of this response (79.7%) was from rural living candidates. This research **conclusion** Patient attitude regarding their life, disease impact and medical service are generally good and **recommend** more interest is to be paid for the patient qualified medical services and social support and showed a **limitation** of being non-comparative, descriptive approach needs to be corresponded later with a more analytic data.

Keywords: thalassemia, sickle cell, satisfaction, QOL

Background

Thalassemia syndromes and sickle cell diseases spectrum are inherited blood disorders, which can lead to life-threatening events and chronic organ damage. Recent advances in treatments have increased life expectancy, and hemoglobinopathies have become chronic illnesses with social and emotional impairments [1,2].

Lifestyle and quality of life Although TDT is burdensome conditions, requiring life-long treatment and close follow-up and can often be complicated by complications arising from many different systems, patients with optimally treated thalassemia can now enjoy a near-normal life and lifestyle, and experience full physical and emotional development from childhood to adulthood [2]. Health-related quality of life is a complex outcome that has been increasingly incorporated in clinical research and clinical practice worldwide, although with regional differences. Disease-specific outcomes (pain for SCD and transfusion burden for thalassemia) and healthcare system characteristics, particularly in low-income countries, have an impact on patient life and attitudes and should be considered in healthcare plans [1].

Thalassaemic patients tend to be diagnosed with psychiatric disorders and it seems that they do not feel severe pain. More quantitative and comprehensive studies have to be conducted in order to estimate specific effective factors in psychosocial health [3].

An unfortunate fact is that approximately 80% of the annual births of babies with these conditions occur in low- or middle-income countries, many of which have extremely limited facilities for their control and management [4].

Such a qualitative and quantitative burden creates the need for issuing specialized centers for hereditary blood diseases in all the areas in which these diseases prevail. It takes upon itself the task of diagnosing, following up, treating and providing the necessary medical service according to national and international treatment guidelines determined by solid scientific institutions. Which is logically to be multidisciplinary in accordance with internationally agreed specifications [5]. Drug availability and feasibility and minimal adverse reaction play a great role in patient adherence and wellbeing but concerted efforts were initiated in tackling DRP with regulatory bodies putting greater emphasis on pharmacovigilance and the World Health Organization (WHO) meeting for a reduction in medication-related harm by 50% to facilitate efficient and sustainable healthcare.

Globally, thalassemia is the most common hereditary hemoglobinopathy, and occurs in 4.4/10,000 live births. Thalassemia is common in the East Mediterranean region, where the prevalence of β -thalassemia is 9.0 per 1000 [7]. The prevalence of thalassemia had increased from 33.5/100,000 in 2010 to 37.1/100,000 in 2015, while the incidence rate had decreased from

72.4/100,000 live births to 34.6/100,000 live births between 2010 and 2015. β -Thalassemia major (β -TM) represented 73.9% of all types of thalassemia. About 66.0% of patients were under 15 years old; 78.8% were offspring of parents who were related, and 55.9% had at least one complication, The last published (at 2015) estimated total number of registered cases of thalassemia in Iraq is 13390 giving a prevalence of 3.4/10000, The highest prevalence was registered in Basra province [7,8].

Different complications including IOL, viral hepatitis, endocrinopathies and others were registered in different percentages in Iraqi patients [8,9].

Historical Background

Almost all the diagnosed patients in Basra are registered in the hereditary blood diseases center which been issued since 1998 as a day clinic within the setting of Basra maternity hospital, specialized center started thereafter at 2008 registering and offer service to all age groups, Because of the very large expansion of the number of patients and the need to improve the type of service and its specialization, an adult center was established, separated from the children's center, so that each one of them would be in a separate hospital, and the Children's Hereditary Blood Diseases center would start its work from July 26, 2022.

Still a large cohort is registered in pediatric center and a meticulous service is currently offered and developed necessitating to have an audit and evaluation for both the burden of the services and sampled patient attitude and satisfaction status.

This is not the 1st status that conducted in Basrah for evaluating this quantitative issue.

Objectives

- 1) General elaboration of patient single centre statistics
- 2) General statistical figuring health services offered by the centre
- 3) Statistical highlights of the patient attitude, QOL

Table 1: Demographical data distribution of the center population

Variables		NO. (No.3325)	Percentage
Age (years)	<1 year	24	0.72%
	1-5 years	598	17.98%
	6-15 years	2703	81.29%
Gender	Male	1830	55.04%
	Female	1495	44.96%
Educational level	Illiterate	1739	52.30%
	Primary	733	22.05%
	Secondary	853	25.65%
Address	Center	1249	37.56%
	Periphery	2076	62.44%
No of child affected	1 patient	806	24.24%
	2 patients	291	8.75%
	3 patients	64	1.92%
	4 or more patients	7	0.21%
Disease category	β Thalassemia major	667	20.06%
	Thalassemia intermedia	481	14.47%
	Sickle cell diseases	2027	60.96%
	Others	150	4.51%

Table 2: The demographical data distribution of the studied sample

Variables		Frequency	Percentage
Age (years)	Mean± SD	9.70± 4.31	
	1-5	13	11.6%
	5-12	71	63.4%
	>12	28	25.0%
Gender	Male	57	50.9%
	Female	55	49.1%

Method, population, statistics

Method: A cross sectional descriptive study had been conducted during the period from August 2022-May 2023 two sets of data had been collected; general data about all the registered patient include demographic variables of disease categories, age grouping, gender, family size, no. of effected children, family size and patient/ parental education beside data about the medical services offered including outpatients, blood transfusion day clinic and in patient services, complications registered for both general and the selected sample also collected. for having feasible and accessible method of evaluating patient attitudes and satisfaction scales a well-structured and locally reviewed questionnaire had been adopted, applied and preliminary verified by the research group.

Population

112 randomly selected patient and family had been enrolled during their attendance to the routine visit to the center outpatient appointment enrollment criteria include age <15, steady status, thalassemia or sickle cell diseases only. All enrolled patients had been asked for consent to be interviewed by the research team member, the research work had been licensed by the research committee in Basrah health directorate.

Statistics

Data had been collected from both sources in a Microsoft® office 2023 excel database, after which had been analyzed, tabulated selectively graphed in presented all in a descriptive, non-comparative way.

The results

Basrah center for hereditary blood diseases is one the biggest centers on the national level that enroll around of 3325 patients registered

From the total of 112 patient had been randomly selected from outpatient attendance during the research period showed the following characteristics and results.

Residence	Urban	46	41.1%
	Rural	65	58.0%
Educational level	Child	24	21.4%
	Illiterate	5	4.5%
	Primary school	61	54.5%
	Secondary school	22	19.6%
Rate of blood transfusion	<2 weeks	11	9.8%
	2-4 weeks	97	86.6%
	>4 weeks	4	3.6%
Blood group	A+	30	26.8%
	A-	5	4.5%
	AB+	3	2.7%
	AB-	4	3.6%
	B+	36	32.1%
	O+	28	25.0%
	O-	6	5.4%

Table (1) showed the demographic distribution of the studied sample, it showed that most of the candidates were of 5-12 years age group, equal male: female presentation, mostly rural living, primary

school attendance, transfused every 2-4 weeks and of B+, A+, O+ blood group predominance, that make the sample almost presentative and heterogenous to serve the research objectives.

Table 3: The patient's family characteristics

Variables		Frequency	Percentage
Paternal educational level	Illiterate	12	10.7%
	Primary	47	42.0%
	Secondary	35	31.3%
	Higher education	18	16.1%
Maternal educational level	Illiterate	22	19.6%
	Primary	42	37.5%
	Secondary	43	38.4%
	Higher education	5	4.5%
Family number	<5	16	14.3%
	5-7	79	70.5%
	>7	17	15.2%
Paternal occupation	Employee	54	49.2%
	Non-employee	57	50.8%
Maternal occupation	Employee	8	7.1%
	Non-employee	104	92.9%
The influence of the disease in the family	No influence	89	79.5%
	Contraception	14	12.5%
	Marriage of the father with the second wife	7	6.3%
	Others	2	1.8%
No. of family members affected	1	47	42.0%
	2	44	39.3%
	3	20	17.9%
	4	1	0.9%
Degree of consanguinity	First degree	66	58.9%
	Second degree	20	17.9%
	No consanguinity	26	23.2%

Table (2) that present family characteristics showed that most of fathers were only primary school attendant, while mother showed near equal primary and secondary teaching level, a paucity in our sample in parental higher education

Most of the families are large size (5-7) in 70.5 %, the vast majority of mothers were non-employed while only 49.2 % of the fathers were employed, consanguinity marriage was evident in a (77.7%), most of the families (80.3%) involve less than 3 effected child, family breakage or social breakage was not evident in (79.5%).

Table 4: The patients Likert scale regarding the management received.

Variables		Frequency	Percentage
The quality of life	Not good	14	12.5%
	Fair	71	63.4%
	Good	20	17.9%
	Very good	7	6.3%
Satisfaction about the health	Very dissatisfied	1	0.9%
	Dissatisfied	19	17.0%
	Fair	60	53.6%

	Satisfied	32	28.6%
	Very satisfied	1	0.9%
Physical pain which interrupts the daily activity	Very dissatisfied	0	0.0%
	Dissatisfied	15	13.4%
	Fair	64	57.1%
	Satisfied	31	27.7%
	Very satisfied	2	1.8%
Acceptance of the external look	Very dissatisfied	0	0.0%
	Dissatisfied	5	4.5%
	Fair	83	74.1%
	Satisfied	24	21.4%
	Very satisfied	0	0.0%

Three levelled Likert scoring toward different variables showed the following distribution, as a general QOL scoring most of the studied ample specified fair score in (63.4%), still (12.5 %) showed not good score, (82.20%) were generally satisfied regarding their general

health, 95.50% were showed collective fair and satisfied score in regard of acceptance of their general appearance, (27.7%) did agreed that physical pain is affecting their life.

Table 5: patient attitude towards medical services

Variables	Frequency	Percentage
Source of medical information	From the doctor	104 92.9%
	From social media	7 6.3%
	Others	1 0.9%
Satisfaction regarding the received medical services	Very dissatisfied	20 17.9%
	Dissatisfied	57 24.1%
	Fair	27 50.9%
	Satisfied	8 7.1%
Medical management needed for normal daily activity	No need	2 1.8%
	Fair	33 29.5%
	Need	71 63.4%
	Need very much	6 5.4%
Satisfaction regarding the received medical services at the center	Very dissatisfied	0 0.0%
	Dissatisfied	1 0.9%
	Fair	45 40.2%
	Satisfied	63 56.3%
	Very satisfied	3 2.7%
Satisfaction regarding the medical staff who managed you at the center	Very dissatisfied	0 0.0%
	Dissatisfied	0 0.0%
	Fair	39 34.8%
	Satisfied	69 61.6%
	Very satisfied	4 3.6%
Satisfaction regarding the accessibility to the medical management	Very dissatisfied	25 22.3%
	Dissatisfied	48 42.9%
	Fair	33 29.5%
	Satisfied	6 5.4%
	Very satisfied	0 0.0%

Source of medical information was mostly the specialised doctor, (24.1%) were dissatisfied regarding general health system while 58% showed collective of fair and satisfied score, (63.4%) were in daily need for medical assistance, 96.4 % showed collective fair and satisfied in regarding the medical service offered from the centre

(56.3%) were satisfied, mostly (61.6 %) were satisfied regarding medical staff management were 34.8% showed dissatisfaction, accessibility to medical service was dissatisfied in (42.9 %) most of this response (79.7%) was from rural living candidates.

Table 6: The Disease related complications in the selected sample

Complication	Frequency	Percentages
Elevated serum iron	90	44%
Joint problems	28	14%
Hypersplenism	27	13%
Delayed sexual maturity	16	8%
Splenectomy	14	7%
Hepatitis C virus	13	6%
Osteoporosis	7	3%
Gall stone	4	2%
Heart failure	3	1%

Hepatitis B virus	0	0
Human immunodeficiency virus	0	0%
Hypothyroidism	1	0%
Respiratory failure	0	0%
Ischemic heart diseases	0	0%
Total	203	100

Disease related complications showed that the most frequent three were IOL, arthropathies and hypersplenism in a percentage of (44%,14%,13%) respectively in the enrolled sample.

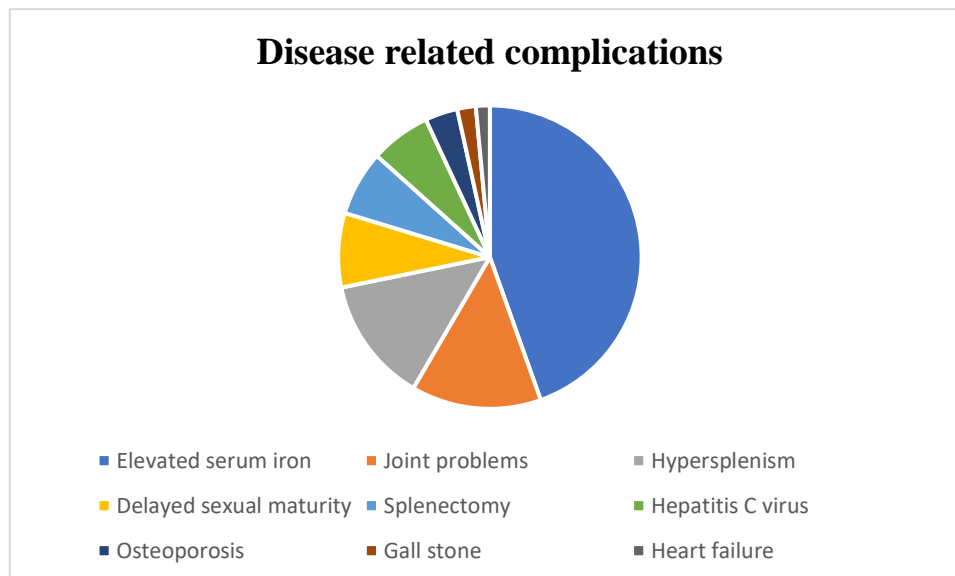


Table 7: The Disease related complications of the whole center population

Variables	Count (No.3325)	Percentage
Splenic related complications	86	2.59%
DM	85	2.56%
Cardiac diseases	133	4.00%
Thyroid related diseases	14	0.42%
Parathyroid hypoplasia	0	0.00%
Growth restriction or delay	103	3.10%
Avascular necrosis and arthropathies	125	3.76%
Very frequent or non-remitting Pain crisis	293	8.81%
Others	119	3.58%
HCV	237	7.12%
HBS	6	0.18%
HIV	0	0%
Death of last 10 years	205	6.17%

Discussion

Basrah centre for hereditary blood diseases contain a large cohort of heterogenous blood disease that are all categorised as hereditary, from them sickle cell diseases followed by thalassemia syndromes have its predominancy, Most of the families are large size (5-7) in 70.5 %, the vast majority of mothers were non-employed while only 49.2 % of the fathers were employed, consanguinity marriage was evident in a (77.7%), most of the families (80.3%) involve less than 3 effected child, in correspondence to data from Nineveh study at 2018 same characteristics of family size, consanguinity marriage and parental education but higher percentage of non-employment in our cohort fathers, with a higher number of effected Childs in the families enrolled [11].

Family breakage or social breakage was not evident in (79.5%) which greatly lesser than another studies in Iran [10] but it close to Nineveh cohort in which 24.9% of the marriages were threatened by divorce [11].

96.4 % showed collective fair and satisfied in regarding the medical service offered from the centre (56.3%) were satisfied, mostly (61.6 %) were satisfied regarding medical staff management

were 34.8% showed dissatisfaction a similar score in a Jordanian survey in which 81.1% of the participants were highly satisfied with the overall nursing care [12].

95.50% were showed collective fair and satisfied score in regard of acceptance of their general appearance, a thing had been differently expressed by a Thailand study in which the study results indicated that adolescents with thalassemia perceived their body image at a poor level. Patient's age was negatively correlated with body image ($r = -.18, p < .05$) [13,14], (27.7%) did agreed that physical pain is affecting their life, a study done in Greece the majority of the studied patients scored between 1 and 3, meaning that they were feeling mild pain [9,14].

General QOL scoring most of the studied ample specified fair score in (63.4%), still (12.5 %) showed (not good) scoring, a study in Genoa did also showed An improvement was observed in most SF-36 scales in 2009 as compared with 2001, particularly in the Mental Health scale [15], QOL is still almost are lower than control groups is more than a study in middle east region [16,17], Self-efficacy and health promotion were an evident supporters to the patient QOL, satisfaction score in more than one series include Basrah [18,19].

Source of medical information was mostly the specialised doctor, a study in USA did show other sources in getting disease awareness as more than 60% of the respondents reported gaining awareness regarding SCD through antenatal care (51%) and schools (17%), as opposed to public awareness campaigns (8%) [20].

And the same in Egypt in which educational programs for thalassaemic children and their nurses regarding chelation therapy and its importance in preventing thalassemia complications is established [21].

(24.1%) were dissatisfied regarding general health system while 58% showed collective of fair and satisfied score, (63.4%) were in daily need for medical assistance, accessibility to medical service was dissatisfied in (42.9 %) most of this response (79.7%) was from rural living candidates.

Disease related complications showed that the most frequent three were IOL, arthropathies and hypersplenism in a percentage of (44%,14%,13%) respectively in the enrolled sample, which is similar to another study done by Sadullah et al.in Northern of Iraq in which IOL on chelation was (94.7%) while (38.0%) got splenectomised, whoever more percentage of arthropathy was encountered in our cohort which is clearly due to the predominance of sickle cell disease in our patients [2,8,22,23].

Conclusions

- 1) Basra center for pediatric hereditary blood diseases is a large center with large cohort of patient registered and enormous medical services offered
- 2) Patient attitude regarding their life, disease impact and medical service are general good with certain limitation regarding accessibility for rural area.
- 3) Complication profile is corresponding to the national figure except in the evidence of high percent arthropathic complications.

Recommendations

- 1) More interest is to be paid for the patient qualified medical services and social support
- 2) Larger sampled studied to be done to elaborate factors correlated with the dissatisfactions and patient negative attitudes

Limitations

- 1) Small sample, non-adult involving was studied need to be subsisted with a large, long period, heterogenous age grouped sample
- 2) Non comparative, descriptive approach need to be corresponded later with a more analytic data.

Disclaimer

The authors have no conflict of interest

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