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Psychological Problems among Different Hereditary Blood Disease in Basrah, A Cross Sectional Study

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ABSTRACT

Hereditary blood disease are so common inherited problems in the world and in Iraq ,as far as the life span of the patients did increased psychosocial problems are greatly expected to increased and were studied through a different series through out the world ,the problem was understudied on the national prospect that nictitate a study to highlight the issue

methodes:104 different diagnoses hereditary blood disease patient were enrolled in this cross sectional study that depend on direct interview and fill of 2 revised questionnaire that covered psycological,social and educational impact of the disease in a period of 6 months in Basra center for hereditary blood disease

results: More than 50.96 % showed agreement toward being hopeless because of the illness,58.65 % agree for being nervous and upset ,59.62% for feels depressed and sad ,50% feel anxious for their future and 50.92% feel nervous because of the illness)

Existence of psychological problems among the patients studied did concluded and issuing screening for the problems among the patients and establishing psychological help programs did recommended.

KEYWORDS: thalassemia, sickle cell, mental, psychological, Likert score. GHQ12

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BACKGROUND

Thalassemia and sickle cell are the most prevalent genetic diseases in the world. Over recent decades, due to significant advances in medical science and the treatment of diseases, the life span of thalassemia and sickle cell patients has increased to more than 50 years [(1),(2)].

Sickle cell anaemia, which is an inherited condition in an autosomal recessive pattern, is scattered in many parts of the world like Italy, Greece, and Central India, and in some African countries [(3),] Presence of patients with SCA will lead to stress, emotional, and social disturbances among families[(4)] and it would be expected that the children with SCA are at high risk of developing psychosocial problems[(5)], Similarly, thalassaemia is also a group of inherited blood disorders which is caused by the reduction or absence of haemoglobin in the red blood cells. The hallmark feature of this disease is anaemia which can lead to breathlessness and fatigue, frequent infections, and other complications, i.e., enlarged spleens and stunted growth, which can lead to bone deformation, all these influences have their impact on the patient psychological state [(6),(7)]

Thalassemia effect on both patient and families is also recognized and had been elicited in a study that In all countries the disease seemed to have a binding effect on the family, thus mobilizing adaptive mechanisms. Father's low education level and the presence of major medical complications were predictors of poor family adjustment. Differences between and within countries may well reflect differences in health policies, existing level of socio-economic development, and in the cultural patterns in coping with a chronic illness [(8)].. In middle east region this subject had its impact that had been studied for example in Saudi Arabia by Dairi et al in whom study they found that most sickle cell participants (85.6%) were found to have depression in Mekka region [(9)] while Omani pilot study of 28 TM patients suggested that having a diagnosis of TM was

significantly associated with symptoms of depression ($p < 0.001$) and anxiety ($p < 0.001$) [10]

Beyond the medical condition, individuals with haemophilia from the other side commonly face several psychosocial challenges as stressed by WHF publications. Social workers, psychologists, and counsellors play a crucial role in helping people with haemophilia and their families adapt and learn to cope[11]

In Iraq many studies discussed the disease related QOL especially for sickle cell disease [12] and thalassemia [13] but still there is a paucity in highlighting the psychosocial impact of registered patients with hereditary blood diseases in different regions of Iraq which necessitate such a study,

Basra center for hereditary pediatric blood disease is one the largest centres in Iraq in which more than (7685) patients were registered with thalassemia, sickle cell disease, and bleeding disorders (2073), (5270), (342) respectively for which this study had been conducted to elicits the existence of such comorbid important impact in those patients

METHODOLOGY AND POPULATION

Method: A prospective cross-sectional study had been conducted by direct inquiry via an already revives questionaries that had been set to evaluate pomological status of the patients and disease impact on psychosocial and educational status.

Researchers did adopt 2 questionaries: a multi-question forms that cover psychological variables in 17 questions, social attitude in 8 questions and educational impact and status in 6 questions in all these three domains 5 level Likert score was estimated.

The second forms had been adopted was the general health score (GHQ)12 Godelberg 1988, in which 12 three levels questions did covered the psychological status regarding depression and stress in both a negative or positive way followed by collection the each item score and finding the total sum of them for each patient enrolled in the study, to reach for a 3 quantitative categorisation of typical (less than 13), stressed (13-24), a psychological risk (above 24) from the total 36 score .

For both adopted revised form (see appendix) the researchers depend on the direct interview query to fill the questionnaire, before that a small pilot sample of 12 patient had been tested to evaluate the validity and feasibility of the questionnaires

Population 104 patients and their families all were diagnosed with one the major hereditary blood disorders: thalassemia, sickle cell diseases and hemophilia (31,72,3) respectively had been enrolled by a random selection all were already registered in BCHBD, during the period of 6 months from August 2022 to February 2023 their ages were divided into 3 categories (12-15,16-18,19-30) years old of different genders and social status and residency for both them and families

Statistics Data was collected in an electronics researchers filled google forms software using a touch tab.to create an Excel sheet database for all the domains and variables that had been later processed, tabulated and graphed via both Microsoft® Excel® 2019 MSO (Version 2305 Build 16.0.16501.20074) 32-bit, and SPSS 22.

RESULTS

104 patients and families did enroll in the study and answered the structured questionnaire through a direct interview between the research members and the candidates ,63 of them were females 41 were males, ages ranged from 12.2 years to 29.1 years, almost were of lower education level or illiterates,3 of them were inpatient and 101 were outpatient attendants

Table (1) demographic characteristics of the patients

Patients Demographics	Variable	No.	percentage
Age categories	(12-15)	22	21.15
	(16-18)	30	28.85
	(19-30)	52	50.00
Gender	females	63	60.57
	Male	41	39.53
Educational level	Illiterate	7	6.73
	Just read and write	7	6.73
	Primary	31	29.8
	Secondary	51	49.05
	college	8	7.69
Type of patient	In patient	3	2.88
	Outpatient	101	97.11
Type of the diseases	thalassemia	31	29.80
	Sickle cell diseases	72	69.23
	Bleeding disorders	3	2.88
Employment status	Student	32	30.76
	Employed	13	12.5
	No employed	59	56.73

Admission frequency	None	44	42.30
	0-3	33	31.73
	4-6	8	7.69
	more	17	16.34

Table (2)complication profile of the enrolled patients.

Disease type	Complication	No.	percentage
haemophilia complication	(arthropathy)	1	0.96
hemoglobinopathy complications	Iron overload	19	18.26
	congestive heart failure	1	0.96
	viral hepatitis	8	7.69
	endocrinopathy	3	2.8
sickle cell complication	sequestration	40	38.46
	repeated vasoclosive pain	7	6.73
	acute chest syndrome	27	25.96
	strokes	5	4.80
	others	3	2.88

Complication profile of the enrolled patients showed that the most prevalent complication in ß thalassemia patients was IOL ,in sickle cell disease was sequestration and acute chest syndrome followed by repeated vasoclosive crises while only one homophilic pt did present with arthropathy .

Sickle cell disease complications was evident in 78.83 % of the enrolled patients.

Table (3) Likert score of the response tward phycological variables

	I strongly agree		I agree very much		I agree moderately		I agree to a small extent		I do not agree	
type psychological problem	No.	percentage	No.	percentage	No.	percentage	No.	percentage	No.	percentage
I feel helpless because of my illness	29	27.88	24	23.08	5	4.81	25	24.04	21	20.19
I get nervous and upset when I think about my illness	34	32.69	27	25.96	9	8.65	15	14.42	19	18.27
I get upset when I need to help others when I'm sick	20	19.23	16	15.38	4	3.85	18	17.31	46	44.23
I feel depressed and sad because of my illness.	31	29.81	31	29.81	8	7.69	17	16.35	17	16.35
The pitying looks of others bother me	28	26.92	19	18.27	3	2.88	12	11.54	42	40.38
Illness makes me feel that it is an obstacle to achieving my future goals	17	16.35	24	23.08	8	7.69	25	24.04	30	28.85
It's hard to rely on myself to solve my problems	16	15.38	18	17.31	10	9.62	18	17.31	42	40.38

I find it hard to make my decisions because of my illness	15	14.42	12	11.54	13	12.50	22	21.15	42	40.38
I feel embarrassed when I experience bouts of pain in front of you	20	19.23	19	18.27	5	4.81	15	14.42	45	43.27
I despair when I remember my illness	22	21.15	24	23.08	12	11.54	23	22.12	23	22.12
I feel that my illness represents psychological pressure for me.	28	26.92	23	22.12	19	18.27	15	14.42	19	18.27
I suffer from a constant struggle with myself because of my illness	19	18.27	24	23.08	9	8.65	32	30.77	19	18.27
I feel dissatisfied with the way my body looks because of my illness	10	9.62	15	14.42	6	5.77	10	9.62	63	60.58
I feel anxious about the future because of my illness	24	23.08	28	26.92	6	5.77	19	18.27	26	25.00
I feel that my spirit drops easily when I remember my illness	21	20.19	23	22.12	8	7.69	21	20.19	31	29.81
I feel nervous because of my illness	28	26.92	24	23.08	13	12.50	14	13.46	24	23.08
I get scared when I think about my future career because	19	18.27	18	17.31	20	19.23	17	16.35	28	26.92

More than 67.31% agreed in 3 levels (moderate, very much and strongly) for feeling that the illness represent a psychological pressure to their lives

More than 50.96 % showed agreement (Very much& strong agreement) toward being hopeless because of the illness,58.65 % agree for being nervous and upset ,59.62% for feels depressed and sad ,50% feel anxious for their future and 50.92% feel nervous because of the illness)

for a lesser degree of agreement, the patient enrolled responded to the questions of the pitying looks of others bother me (45.19%), I despair when I remember my illness

I feel that my spirit drops easily when I remember my illness(42.31%),I suffer from a constant struggle with myself because of my illness(41.35%),Illness makes me feel that it is an obstacle to achieving my future goals(39.43%), I feel embarrassed when I experience bouts of pain in front of you(37.5%), I get scared when I think about my future career because of my illness(35.58%), I get upset when I need to help others when I'm sick(34.61%),It's hard to rely on myself to solve my problems(32.69%),while showed less agreement towards the questions of I find it hard to make my decisions because of my illness(25.96%), I feel dissatisfied with the way my body looks because of my illness(24.04%) the last point showed a great disagreement which represent a regret toward the effect of body look .

Table (4) Likert score of the response toward social variables

social domines	I strongly agree		I agree very much		I agree moderately		I agree to a small extent		I do not agree	-
I live isolated because of my illness	9	8.65	5	4.81	10	9.62	5	4.81	74	71.15
I feel angry at my community's customs of consanguineous marriage because it is responsible for my disease	19	18.27	16	15.38	12	11.54	21	20.19	35	33.65

I find it difficult to move around due to illness	20	19.23	22	21.15	9	8.65	13	12.50	39	37.50
I prefer not to participate in social events because of my illness	4	3.85	16	15.38	18	17.31	15	14.42	51	49.04
I miss being able to help others because of my illness	12	11.54	20	19.23	8	7.69	14	13.46	50	48.08
My relationship with my community and people decreased because of my illness	7	6.73	17	16.35	13	12.50	22	21.15	45	43.27
I get upset when my family treats me differently from the rest of my brothers	6	5.77	9	8.65	6	5.77	18	17.31	64	61.54
I feel that I have no role in my family because of my illness	3	2.88	7	6.73	22	21.15	23	22.12	49	47.12

This table showed that the enrolled patient showed almost disagreement towards 6 social domines in the questionnaire which were :-

I live isolated because of my illness (71.15%),I get upset when my family treats me differently from the rest of my brothers (61.54%), I prefer not to participate in social events because of my illness (49.04%), I miss being able to help others because of my illness (48.08%), I feel that I have no role in my family because of my illness (47.12%) My relationship with my community and people decreased because of my illness (43.27%),

While the disagreement did decline with higher collective agreement score (I agree moderately, I agree very much and I agree strongly) in 2 domains which were:-

I find it difficult to move around due to illness (37.5%), I feel angry at my community's customs of consanguineous marriage because it is responsible for my disease (33.65%) for which the agreement were (49.03%) (45.19%) respectively.

Table (5) Likert score of the response toward educational variables

Educational domains	I strongly agree		I agree very much		I agree moderately		I agree to a small extent		I do not agree	
	No.	percentage	No.	percentage	No.	percentage	No.	percentage	No.	percentage
My Illness makes me lose my self-confidence while studying	24	23.08	28	26.92	8	7.69	19	18.27	25	24.04
Frequent pain attacks affect my poor academic performance and achievement level	22	21.15	35	33.65	14	13.46	15	14.42	18	17.31
My admission in the hospital leads to a decrease in the level of achievement	29	27.88	28	26.92	9	8.65	10	9.62	28	26.92
I find it difficult to concentrate on studying due to illness	19	18.27	40	38.46	9	8.65	10	9.62	24	23.08
My performance in class is poor because of my illness	25	24.04	30	28.85	11	10.58	13	12.50	23	22.12
I feel low academic achievement motivation because of my illness	20	19.23	34	32.69	14	13.46	13	12.50	21	20.19

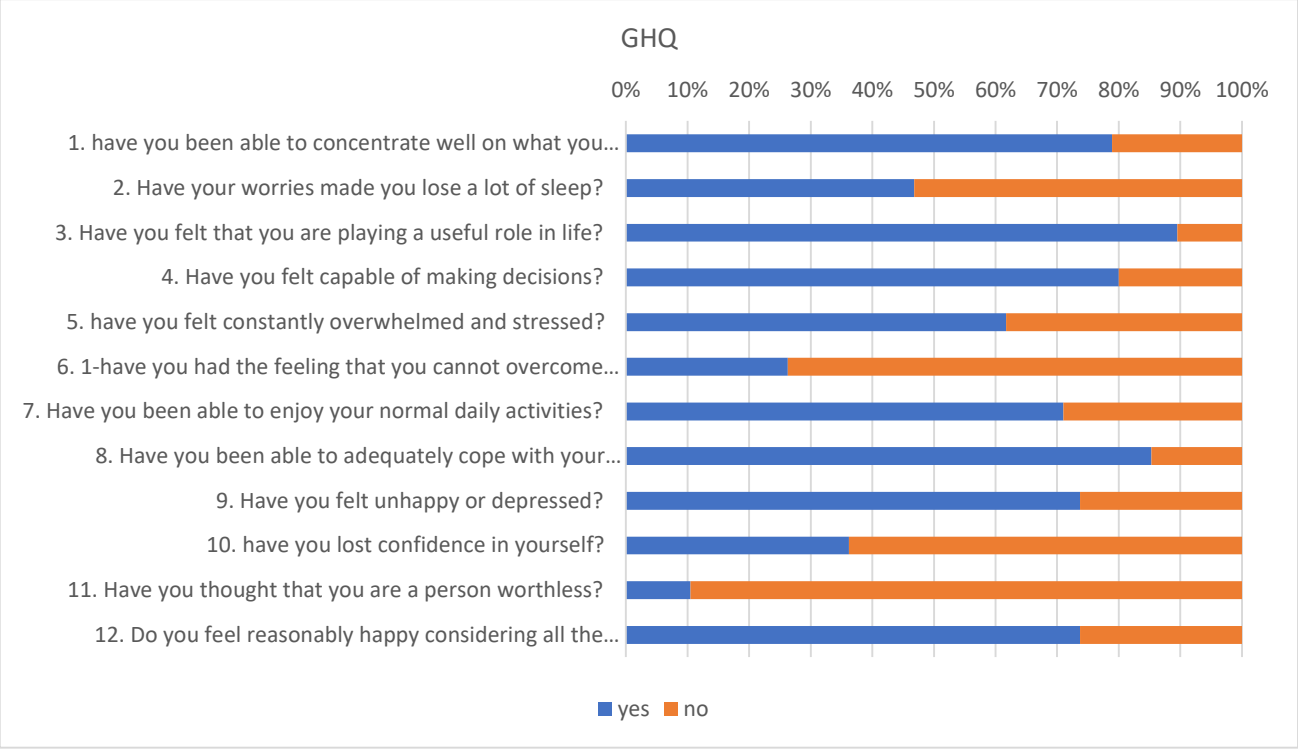
For the educational domains of the questionnaire the patient showed absolute agreement collective score (I strongly agree, I agree very much, I agree moderately) to all the domains that included: -

Frequent pain attacks affect my poor academic performance and achievement level (68.26%), I find it difficult to concentrate on studying due to illness (65.38%), I feel low academic achievement motivation because of my illness (65.38%), My performance in class is poor because of my illness (63.47%), My admission in the hospital leads to a \ decrease in the level of achievement (63.45%)and that My Illness makes me lose my self-confidence while studying (57.69%).

Table (6) Responses toward GHQ 12 Godelberg 1988

general health scoring variables	yes	no
1. have you been able to concentrate well on what you were doing?	78.90	21.10
2. Have your worries made you lose a lot of sleep?	46.80	53.20
3. Have you felt that you are playing a useful role in life?	89.50	10.50
4. Have you felt capable of making decisions?	80.00	20.00
5. have you felt constantly overwhelmed and stressed?	61.70	38.30
6. have you had the feeling that you cannot overcome your difficulties?	26.30	73.70
7. Have you been able to enjoy your normal daily activities?	71.00	29.00
8. Have you been able to adequately cope with your problems?	85.30	14.70
9. Have you felt unhappy or depressed?	73.70	26.30
10. have you lost confidence in yourself?	36.20	63.80
11. Have you thought that you are a person worthless?	10.50	89.50
12. Do you feel reasonably happy considering all the circumstances	73.70	26.30

It showed that the patients studied are mostly fell (able to concentrate well, playing an important role in the life, decision making, overwhelmed and stressed overcome difficulties, able to enjoy, can face and cope problems,) but at the same time they mostly (felt depressed and unhappy, not feeling confident in a 36.2 %, not feeling happy in a 26.3 %), the result also shown in the graph below



Graph (3) Responses toward GHQ 12 Godelberg 1988

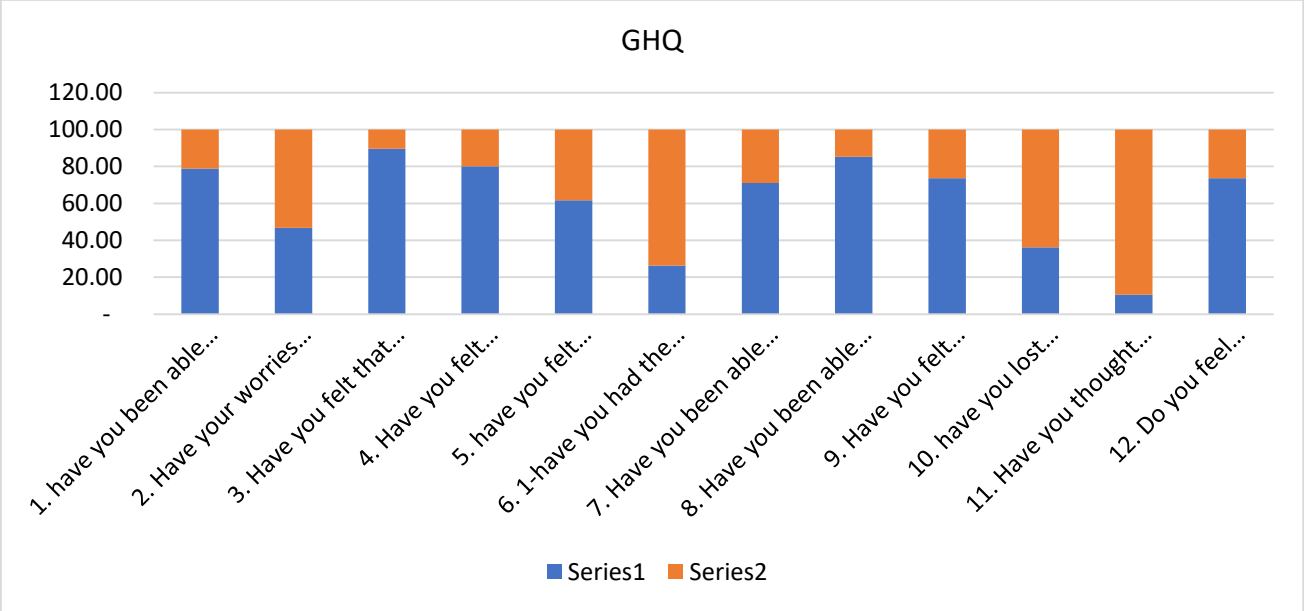


Table (7) distribution of different factors according to the QGH12 score categories

variable							
Patients Demographics	Variable	typical (less than 12)	distressed (13-20)	psychological (above 20)	No.	percentage	P-value
Age categories	(12-15)	14(21.53)	5(22.72)	3(17.64)	22	21.15	
	(16-18)	20(30.76)	4(18.18)	6(35.29)	30	28.85	0.775
	(19-30)	31(47.69)	13(59.09)	8(47.05)	52	50	
Gender	females	42(46.61)	10(45.45)	12(70.58)	63	60.57	0.197
	Male	23(35.38)	12(54.54)	5(29/41)	41	39.53	
Educational level	Illiterate	4(6.15)	1(4.55)	2(11.76)	7	6.73	
	Just read and write	7 (10.77)	0(0.00)	0(0.00)	7	6.73	0.781
	Primary	19(29.33)	7(31.83)	4(23.53)	31	29.8	
	Secondary	26(40.44)	13(59.09)	9(52.94)	51	49.05	
	college	7(10.77)	1(4.55)	0(0.00)	8	7.69	
Type of the diseases	thalassemia	13(20.00)	9(40.91)	7(41.18)	31	29.8	
	Sickle cell diseases	50(76.92)	12(54.55)	10(58.82)	72	69.23	0.231
	Bleeding disorders	2(3.08)	1(4.55)	0(0.00)	3	2.88	
Employment status	Student	21(32.31)	6(27.27)	7(41.18)	32	30.76	
	Employed	6(9.23)	3(13.64)	1(5.88)	13	12.5	0.864
	Not employed	38(58.46)	13(59.09)	9(52.94)	59	56.73	
Admission frequency	None	32(49.23)	10(45.45)	0(0.00)	44	42.3	
	1-3	25(38.48)	2(9.09)	3(17.65)	33	31.73	0.001
	4-6	3(4.62)	5(22.73)	6(35.29)	8	7.69	
	More than 6	8(12.31)	5(22.73)	8(47.06)	17	16.34	
complication profile		9(13.84)	7(31.81)	8(47.05)	24	15.6	0.008
total		65	22	17			

This table is clearly showing that female higher percentage of high GHQ12 score that is categorised as evident of serious psychological troubles was in age groups above 16 years (82.35%), female gender (70.58%), secondary school level (52.94%), sickle cell disease (58.82%),unemployed, student status(52.94%) ,(41.18%) respectively with great paucity of stress in employed patients (5.88%) While it was so clearly that association of higher stress score with the higher

frequency of admissions (47.06%) and evidence of complications (13.84) ,(31.81) , (47.05) .with a mean QGH12 score of 15.6 among those with complications apart from all these correlational evidence of all the variables ,significant association was statistically evident only in relation frequency of admissions and evidence of disease related complications (0.001),(0.008) respectively .

DISCUSSION

More than 67.31% agreed in 3 levels for feeling that the illness represent a psychological pressure to their lives and more than 50.96 % showed agreement toward being hopeless because of the illness,58.65 % agree for being nervous and upset ,59.62% for feels depressed and sad ,50% feel anxious for their future and 50.92% feel nervous because of the illness)

Similarly, Evidence of depressive disorders in hemoglobinopathy patients had been so evident in more than one series like that found in Patients with Beta Thalassemia Major in AL Madinah Munawara, Saudi Arabia where Depression symptoms were detected in 60 % of patients, anxiety symptoms were detected in half of the studied group, and stress symptoms were detected in 38.7% of patients [13].

And in Nigerian series in which he results also showed that depressive feelings (54%) were experienced in almost half the study population. [14],[15] .while in Sudan 45.8% did suffered from depressive disorders[16]

For the psychological queries of I feel that my spirit drops easily when I remember my illness (42.31%),I suffer from a constant struggle with myself because of my illness(41.35%),Illness makes me feel that it is an obstacle to achieving my future goals(39.43%) ,all these threat ideations were also evident in Nigeria study Negative Societal Attitudes/Perception in (62%) , (66%) of the adolescents ,adults studied respectively [14]

For the educational domains of the questionnaire the patient showed absolute agreement collective score for that Frequent pain attacks affect my poor academic performance and achievement level (68.26%), I find it difficult to concentrate on studying due to illness (65.38%), I feel low academic achievement motivation because of my illness (65.38%), in comparison to that found in Sudan About 17.8%, 16.8%, of the patients suffered from school absence, failure to contribute to school activities such as sport, respectively[15]

The agreement towards the questions of: I live isolated because of my illness (71.15%),I get upset when my family treats me differently from the rest of my brothers (61.54%), I prefer not to participate in social events because of my illness (49.04%), in a study on 130 Greece hemoglobinopathy patients Anxiety 18 (23%), insecurity 17 (22%), sadness 12 (15%), anger 10 (13%), loneliness (9%), and disappointment 4 (5%) were the emotions experienced by patients with mood disorders 2 to 3 times per week[17]

The results of Application of the GHQ 12 Godelberg 1988 the patients studied are mostly fell (able to concentrate well, playing an important role in the life, decision making, overwhelmed and stressed overcome difficulties, able to enjoy, can face and cope problems,) but at the same time they mostly (felt depressed and unhappy, not feeling confident in a 36.2 %, not feeling happy in a 26.3 %),all were comparable to a Nigerian study in which Feelings of inadequacy of social contact were significantly associated with high FBS and GHQ12 scores. Some common complaints were: the limitations illness placed on social life; depressive feelings; abnormal habitus; suicidal ideation during crises [18] another series showed that 12% feels that the diseases cause social inferiority and 33.3 % thinks it causes low intelligence [19].correlations of higher Goldberg GHQ12 1988 score with the higher age ,female sex ,work status lower education level and evidence of disease complication was also found in a Syrian study by Huda Gharaibeh et al.on 6-18 years old thalassemic patients from which a strict recommendation and implication for new policies and new roles for the community health nurse and social workers as well as the need for counselling and educational programs for children with thalassemia[20],another 45 thalassemic day care attendant series categorised on base of age group showed a higher risk of psychological problems with increasing age [21].female gender ,higher age ,frequent admissions and crises ,low income were also a risk for depression in sickle cell disease in a study done in sickle cell clinic at Howard University Hospital[22].which all support evidence found in this study.

CONCLUSIONS

1) Psychological, social and educational problems are a significantly exist among the studied randomly selected sample.
2) Threats ideation, fears and negative thoughts are greatly expressed when a suitable evaluation tool is used.
3) Higher score of QGH12 among females, above 16,higher admission frequency ,lower education level, sickle cell diseases and unemployed patients

RECOMMENDATIONS

1) Screening program for early detection of psychological problems is greatly needed to be issued routinely for the attendant of hereditary blood diseases centres.
2) Professional psychologist/psychiatric personal are needed greatly among the faculties of the of hereditary blood diseases centres to establish a solid psychological help programs for the patients
3) Feasible screening tools are needed to be selected for the interviewing with patients to be evaluated psychologically
4) Larger more comparative and analytic studies are needed to be done to highlights the psychological problems among this diseases group involving even evaluating the caregivers, families and it should be preferably multicentre on national base.

5) similar studies are to be done for each disease entity separately with a larger sample
6) Support for the patients towards higher educational levels and being embayed

LIMITATIONS

1) The study was in need for a larger sample size
2) Larger representative bleeding disorders sample was needed
3) More comparative analytical pathway was preferable

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