Assessments Self –Care of Sickle- Cell Patients at Baghdad Teaching Hospitals

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Abstract

Sickle-cell disease (**SCD**)) is a group of genetic disorders that is characterized by the development of abnormal hemoglobin (Hgb S), abnormal red blood cells, and the resultant complications include vaso-occlusive pain crises, acute chest syndrome, acute splenic sequestration& pneumococcal disease.

Objectives of the study: To assess the self efficacy of patients with sickle – cell anemia at blood disease ward in Baghdad Teaching hospital and to find out the association of some demographical characteristics of the sample such as (age , gender, level of education & years of disease affected) with self efficacy. **Methodology**: A descriptive design of study was carried out, for the period 1st Oct, 2017 – 15th of May, 2018, to identify the self – efficacy of sickle cell patients, A 40 patients was participate at the study. The setting was Baghdad Teaching Hospital, Ghazi –Al Hariri Teaching Hospital IBN-Al Belady teaching hospital. **Results:** Most of study participants are females (60.0%) , More than a third are within the age group of (22-25) years-old (35.0%),they were at high school graduate (27.0%), followed by those who are middle school graduates (25.0%), those who are both elementary school graduate and hold a bachelor's degree (15.0%), and those who are unable to read and write (7.5%). More than a half are married (55.0%), followed by those who are married (30.0%), those who are divorced (12.5%). Less than a third are students (n = 12; 30.0%), followed by those who are self-employed (27.5%), those who are out of work (20.0%), those who are officers (12.5%), and those who are housewives .Less than a half reported that their father is the affected person (45.0%), followed by mothers (27.5%), relatives (15.0%), and both parents (12.5%). Regarding health status, the health of the majority are fair (80.0%), followed by those who have poor health (n = 6; 15.0%), and those who have good health (5.0%). More than two-fifth reported that they are hospitalized (4-6) times per year. All patients reported that they have been treated for more than 10 years (100.0%). **Conclusions:** findings of study shows that ,male participants have a better self-efficacy of activity of daily living than female participants of activity of daily living, level of education, age, family ranking & financial social status.

Key words: *Assessments, self -care, Sickle- cell, Patients*

Introduction

Sickle cell disease (SCD) is an inherited blood disorder affecting predominantly persons of African descent [(1).] Diagnosis of SCD is typically made at birth during newborn screening. Disease management focuses on pain, hydration, and preventing infections and other complications that result in vaso-occlusive crises [(2).]Sickle cell disease (SCD) represents a group of serious inherited blood disorders associated with acute and chronic morbidity, recurrent unpredictable and unrelenting episodes of pain, increased risk of infection, stroke, organ damage and other debilitating complications [(3).] The Sickling of the cells causes impaired blood circulation which results in pain. This is the most common complication of sickle cell disease. It can begin as early as infancy and can happen unpredictably throughout life [(4).]Hematopoietic stem cell transplantation has shown promising outcomes, particularly when donors are human leukocyte

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antigen (HLA) matched siblings; however, older age (transplantation has optimal outcomes during childhood) and advanced disease are associated with poor transplant outcomes [5].

Methodology

A descriptive analytic design of study was carried out, for the period 1st Oct, 2017 – 15th of May, 2018, to assess the self – efficacy(care) of sickle cell patients, A 40 patients was participate at the study. The setting was Baghdad Teaching Hospital, Ghazi –Al Hariri Teaching Hospital IBN-Al beldy teaching hospital. Administrative and ethical agreements in order to conduct the study, the researcher first must get the approval of the council of Nursing College for the study and submitted a detailed description including the objectives of the study to the Ministry of Health in Iraq (Department of Planning / Health research section) and the obtain an official permission to carry out the study , The consent form facilitated having access to the hospital facilities, as well as meeting, once written permission was giving by the patients for their participation in the study. The study instrument was composed of two parts, the first part was socio- demographical information& clinical characteristics consist of 15 item which include gender, age, level of education, occupation, health Status & other items. The second part was the scale to measure the self- efficacy with some modification to be adapted the sickle- cell Iraq- patients & it was consisted of 31 items.

The self –efficacy scale was rated & scored by assigning each sickle- cell adult patients response an ordinal value, three levels options (sure, some sure never). The validity of the questionnaire was determined through a panel of (15) expert. The reliability of the present study instrument was determined by Test-Retest, the result was coefficients for the patients (r=86). Data were analyzed through the application of descriptive & inferential data analysis approach by using SPSS version 20.

Results

Table(1) :Distribution of Participants' Self-care responses.

List	Items	Always	Sometimes	Never	Mean (SD)	Ass.
1	How sure are you that you can do something to cut down on most of the pain?	(7.5%)	(82.5%)	(10.0)	1.98 ± .42	Fair
2	How sure are you that you can keep doing most of the things you do day-to-day?	(37.5%)	(57.5%)	(5.0%)	2.32 ± .57	Fair
3	How sure are you that you can keep sickle cell disease pain from interfering with your sleep	(22.5%)	(70.0%)	(7.5%)	2.15 ± .53	Fair
4	How sure are you that you can reduce your sickle cell disease pain by using methods other than taking medication	(15.0%)	(72.5%)	(12.5%)	2.02 ± .53	Fair
5	How sure are you that you can control how often or when you get tired?	(17.5%)	(80.0%)	(2.5%)	2.15 ± .42	Fair
6	How sure are you that you can do something to help yourself feel better if you are feeling sad or blue?	(32.5%)	(60.0%)	(7.5%)	2.25 ± .58	Fair
7	As compared with other people with sickle cell disease, how sure are you that you can manage your life from day-to-day?	(52.5%)	(47.5%)	(0.0%)	2.52 ± .50	Good
8	How sure are you that you can manage your sickle cell disease symptoms so that you can do the things you enjoy doing?	(27.5%)	(70.0%)	(2.5%)	2.25 ± .49	Fair
9	How sure are you that you can deal with the frustration of having sickle cell disease?	(20.0%)	(72.5%)	(7.5%)	2.12 ± .51	Fair
10	How sure are you that you can marry and make a family?	(67.5%)	(32.5%)	(0.0%)	2.68 ± .47	Good
11	How sure are you that you can get a job?	(27.5%)	(67.5%)	(5.0%)	2.22 ± .53	Fair
12	How sure are you that you can be in high places?	(12.5%)	(32.5%)	(55.0%)	1.58 ± .71	Poor

Cont... **Table(1) :Distribution of Participants' Self-care responses.**

13	How sure are you that you can keep a balanced nutrition system?	(47.5%)	(40.0%)	(12.5%)	2.35 ± .70	Good
14	How sure are you that you can be away of dehydration?	(82.5%)	(17.5%)	(0.0%)	2.82 ± .38	Good
15	How sure are you that you can keep yourself calm (not feel with cold)?	(87.5%)	(12.5%)	(0.0%)	2.88 ± .33	Good
16	How sure are you that you Can walk?	(100.0%)	(0.0%)	(0.0%)	3.00 ± .00	Good
17	How sure are you that you can run?	(27.5%)	(67.5%)	(5.0%)	2.22 ± .53	Fair
18	How sure are you that you can do sports or exercise?	(15.%)	(60.0%)	(25.0%)	1.90 ± .63	Fair
19	How sure are you that you can left heavy things?	(7.5%)	(22.5%)	(70.%)	1.38 ± .62	Poor
20	How sure are you that you can take bath or shower?	38 (95.0%)	(5.0%)	(0.0%)	2.95 ± .22	Good
21	How sure are you that you can do chores around house?	(37.5%)	(60.0%)	(2.5%)	2.35 ±.53	Good
22	How sure are you that you can doing things other peers do?	(32.5%)	(67.5%)	(0.0%)	2.32 ± .47	Fair
23	How sure are you that you Have low energy?	(7.5%)	(80.%)	(12.5%)	1.95 ± .45	Fair
24	How sure are you that you Feel afraid or scared?	(0.0%)	(17.5%)	(82.5%)	1.18 ± .38	Poor
25	How sure are you that you Feel sad or blue?	(17.5%)	(52.5%)	(30.0%)	1.88 ± .68	Fair
26	How sure are you that you Feel angry?	(75.0%)	(22.5%)	(2.5%)	2.72 ± .50	Good
27	How sure are you that you have Trouble sleeping?	(5.0%)	(72.5%)	(22. 5%)	1.82 ± .50	Fair
28	How sure are you that you Worry about what will happen?	(82.5%)	(10.0%)	(7.5%)	2.75 ± .58	Good
29	How sure are you that you Hard to concentrate?	(40.0%)	(50.0)	(10.0%)	2.30 ± .64	Fair
30	How sure are you that you Forget things?	(13.5%)	(55.0%)	(32.5%)	1.80 ± .64	Fair
31	How sure are you that you Hard to keep up when play with others?	(22.5%)	(62.5%)	(15.0%)	2.08 ± .61	Fair
					68.90 ± 7.96	

Cut-off-point: Poor = 1-1.66, Fair = 1.67-2.33, Good = 2.34-3.00

Table (1) shown that most participants experience very poor self-care in the items 24, 19, 12 ,30 ,27 ,25 ,18 ,23 ,1 ,4 (Mean [SD] = 1.18 ± .38, 1.38 ± .62, 1.58 ± .71, 1.80 ± .64, 1.82 ± .50, 1.88 ± .68, 1.90 ± .63, 1.95 ± .45, 1.98 ± .42, 2.02 ± .53) respectively.

Table (2) : Association of sample self-care response & gender groups.

Ranks					Mann-Whitney U	Asymp. Sig.
	Gender	N	Mean Rank	Sum of Ranks		
Self-care	Male	16	32.47	519.50	.500	.000
	Female	24	12.52	300.50		
	Total	40				

Table (3): Association of sample response of self-care among age groups.

Ranks				Chi-Square	Df	Asymp. Sig.
	Age	N	Mean Rank			
Self-care	18-21 years	8	36.50	33.016	3	.000
	22-25 years	14	24.32			
	26-29 years	12	13.75			
	30-33 years	6	3.75			
	Total	40				

Table (4) : Difference in self-care among the occupation groups .

Ranks				Chi-Square	df	Exact. Sig.
	Occupation	N	Mean Rank			
Self-care	student	12	34.46	34.470	4	.000
	officer	5	26.10			
	gainer	11	15.82			
	jobless	8	11.50			
	housewife	4	2.50			
	Total	40				

Table (5) : Difference in self-care among the family members groups .

Ranks				Chi-Square	df	Exact. Sig.
	Family Members	N	Mean Rank			
Self-care	three	4	37.50	34.312	5	.000
	four	11	31.36			
	five	14	17.54			
	six	7	9.93			
	seven	3	3.00			
	eight	1	1.00			
	Total	40				

Discussion

The result of the study demonstrated that majority of the sample were female at age group of (22-25) years-old, level of education graduated from elementary school, self-employee,

More than two-fifth reported that they are hospitalized (4-6) times per year (42.5%), followed by those who are hospitalized (1-3) times (35.0%), those who are hospitalized (4-6) times (17.5%), and those who are hospitalized (10-12) times (5.0%). All patients reported that they have been treated for more than 10 years (100.0%). The majority reported that they are not alcoholics 90.0%), most are non-smokers (n = 27; 67.5%), and most have fair self-care (67.5%).

Sickle cell disease (SCD) represents a group of serious inherited blood disorders associated with acute and chronic morbidity, recurrent unpredictable and unrelenting episodes of pain, increased risk of infection, stroke, organ damage and other debilitating complications [3,4] .

Distribution of sickle- cell **self- care participant responses,** participants experience very poor self-efficacy in the items 24, 19, 12 ,30 ,27 ,25 ,18 ,23 ,1 ,4 (Mean [SD] = 1.18 ± .38, 1.38 ± .62, 1.58 ± .71, 1.80 ± .64, 1.82 ± .50, 1.88 ± .68, 1.90 ± .63, 1.95 ± .45, 1.98 ± .42, 2.02 ± .53) respectively, moreover,70%of the study sample presents fair for item how sure you that you can reduce pain by using methods other than taking medication, Adults with Sickle Cell Disease (SCD) are a significant population to study when considering self-medication behaviors, as they utilize multiple prescription drugs for management of symptoms related to their disease. Adults living with SCD will demonstrate adverse self-medication practices as recorded on the Actual Meds™ Medication Management System via use of Apple iPad® digital mobile device during a single interview Beyers, Courtney Marie.

Table(3) presented that There is a statistically significant difference between Participants who were within the age group of (18-21) years-old have a better self-care than those who were within the age group of (22-25) years-old, participants' self-efficacy of activity of daily living among age groups (Chi-square = 33.016, df = 3, p-value = .000).

Life expectancy for persons with SCD has recently increased from age fourteen in 1973 to the

mid to late forties in 2004, transforming SCD into a long-term chronic illness. This chronic disorder may result in a lifetime of pain experiences and frequent hospitalizations [7] .There is a statistically significant difference in participants' ,who were unable to read and write have a better self-care than those who were elementary school graduates, those who were middle school graduates, those who were high school graduates, those who hold a bachelor's degree, and those who have other educational qualification. self-efficacy of activity of daily living among the level of education groups (Chi-square = 36.481, df = 5, p-value = .000). Finding showed the Participants who were students have a better self-efficacy than those who were officers, those who were gainers, those who were jobless,. and those who were housewives. There is a statistically significant difference in participants' self-efficacy of activity of daily living among the occupation groups (Chi-square = 34.470 ,df = 4, p-value = .000).Sickle cell disease (SCD) represents a group of serious inherited blood disorders associated with acute and chronic morbidity, recurrent unpredictable and unrelenting episodes ofpain, increased risk of infection, stroke, organ damage and other debilitating complications [3,4].Participants who were 4-6 times have a better self-efficacy than those who were 1-3 times, those who were 7-9 times, and those who were 10-12 times. There is a statistically significant difference in participants' self-efficacy of activity of daily living among the Hospitalization during a Year groups (Chi-square = 33.428 ,df = 3, p-value = .000).In the U.S., this disease primarily affects African Americans. Within this group, there is an incidence of one in 500 births and the sickle cell trait occurs in about one in 12. Sickle cell disease is anautosomal recessive disorder, and males and females are affected equally (Pack-Mabien& Haynes, 2009)[9]. Diagnosis of SCD is typically made at birth during newborn screening. Disease management focuses on pain, hydration, and preventing infections and other complications the result in vaso-occlusive crises [2].

Conclusion

The study concluded that participant of the research experience very poor self- care at most of the items, while there was statistical significant association between gender, which present Male participants have a better self-care of activity of daily living than female participants of activity of daily living, level of education, age, family ranking &financial social status. The researcher recommended to initiated a specialized center for providing medication, care, educational programs, fellow up & financial for sickle cell patients.

Acknowledgements: This research was funded by Authors. Moreover, we would like to thank the study participants and data collectors for their fully participation and responsible data collection.

Conflict of Interest: None declared.

Ethical approval: The study was approved by the Institutional Ethics Committee.

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