

## **BIO-PSYCHOSOCIAL AND CULTURE ASPECTS OF CLIENTS COMPLAINING OF SICKLE CELL ANEMIA AND THALASSEMIA IN SAUDI ARABIA**

**Munirah saad aldossari**

Specialist nursing

Senior health education, Prince sultan military medical city

Master of community health nursing

**Email :** [Muniraa\\_9999@hotmail.com](mailto:Muniraa_9999@hotmail.com)

### **Abstract**

The aim of this study is to assess bio psychosocial and culture aspects of sickle cell anemia and thalassemia among Saudi population. **Design:** Design of this study is quantitative, cross sectional design. **Study settings:** Prince Sultan Riyadh Military Medical City and King Khalid University Hospital. **Study subjects:** The total number of the study sample was 133 Saudi patients. Following the standards rules for sample size calculation. Data collected through the use of: **A Structured Self-Administered Questionnaire** was developed by the researcher after reviewing literature And Include 6 subcategory demographic data, medical history, biological/ physical aspect, psychological aspect, social aspect, and culture aspect.

**Results:** the overall mean (1.77) which indicate that bio- psychosocial aspects and the overall mean (2.15) which indicate that the cultural aspects of people with sickle cell anemia and thalassemia. **Conclusion:** from this present the most important relations were affiliated to psychological aspects of the studied clients furthermore there is a significant relation between psychological aspect and demographic social aspect "marital status".

**KEYWORDS:**

(SCD) Sickle cell diseases, (BPS) model- bio-psychosocial model, (ADL) Activity daily living,(HRQOL) Health Related Quality Of Life, (Hb) Hemoglobin, (SES) Socioeconomic status.(QOL) Quality Of Life, clients, thalassemia.

### **Introduction:**

clients with hematologic and blood disorders complain of biopsyo-social, and culture aspects despite they are not initial causes, however, health care provider among them nurses generally noticed that those clients are prone to be stressed especially those with sickle cell anemia and thalassaemia.(Dwairy,M.,2009)(Crosby, L. E., Quinn, C. T.et al,2015).Sickle Cell Disease and thalassaemia classified to two main Hemoglobin disorders and in recent years have been acknowledged to have a global impact by the World Health Organization (WHO, 2017).

Sickle Cell Disease comprises a group of inherited red blood cell conditions that result from the synthesis of variant or mutant hemoglobin. Over 300,000 babies are born worldwide with Sickle Cell Disease mostly in low and middle-income countries, with the majority of these births in Africa. Sickle Cell Disease originates in tropical regions. It is predominant among people from African, Asian, Arabian and Mediterranean countries; nonetheless it is a global health problem because of population migration (Anie k a, et al, 2010) (He, Y.et al, 2016).

In Saudi Arabia the prevalence of couples who tested positive for sickle cell was 45.1 (42.4 for carriers and 2.7 for cases) per 1000 persons examined. The prevalence was highest in the Eastern region (134.1 per 1000), followed by Southern and Western regions (55.6 and 28.5 per 1000, respectively) and lowest in Central and Northern regions 13.7 and 13.5 per 1000, respectively. Also the prevalence of couples testing positive for  $\beta$ -thalassemia was 18.5 (18.0 for carriers and 0.5 for cases) per 1000 persons examined. The prevalence was highest in the Eastern region (59.0), moderate in the Southern, and Western and Central regions (14.2, 10.2, and 10.1 per 1000, respectively) and lowest in the Northern region (3.9) (Memish Z et al, 2011).

Psychosocial issues for people with Sickle Cell Disease and thalassaemia their families mainly result from the impact of pain and symptoms on their daily lives, and society's attitudes to Sickle Cell Disease and those affected.(Dwairy.M,2009)(Daniel, L. et al ,2015).

A major area of dissatisfaction was due to lack of social contacts, particularly from friendship and social activities, the ability to form friendship and social networks will greatly influence a person's ability to cope in the society,

in addition to positive social support is a positive. Mediating factors which irrespective of pain controls has been shown to be related to a better quality of life. Adults with sickle cell disease feelings of being isolated by their experience of a sickle cell pain crises and limited social support networks adversely affect pain management with unpredictable pain crises, patients of sickle cell disease may have decreased work productivity, missed work, and school absence that has significant effect on life (Imhonde, H. O., Ndom, R. J. E., &Ehon, A. 2013) (Hensler, M.et al, 2014).

Cultural factors may impact client prognosis & complains particularly what relevant to these problems because of beliefs and traditional practices. Beliefs are usually influenced by cultural and religious values, which influence health behavior such as coping strategies. Studies have shown that religious beliefs play a positive part in coping including prayer, faith in God and doctors, and a hopeful approach to health difficulties (Anie K A. et al ,2010)( Ezenwa, M. O.et al,2016).

The hematology nurse's role is pivotal to the comprehensive care of individuals with sickle cell disease. It centers on providing ongoing education about the disease, ensuring a system of preventive health management, recognition and management of acute illnesses, and the timely coordination and integration of subspecialty care. In addition, the nurse plays a central role in developmental and emotional anticipatory guidance and in the empowerment of the patient and family for their own advocacy (Okpala, I.,et al, 2002)( Pettersson, M. et al,2014)(Mallari, M. S. N.et al 2016).

The bio-psycho-social model reflects the understanding that human beings are biological, psychological and social creatures all at the same time. People seeking to benefit from scientific wisdom for purposes of helping themselves better manage life problem are wise to copy this comprehensive professional approach and do what they can to learn about these three important aspects of human experience.(Santrock, J. W. (2007)( Crosby, L. E.et al,2015).

### **Significance of the study:**

Assessing clients should base on biopsychosocial, cultural, and spiritual approach of care. Hence, researcher should view the patient as biological, psychological, social, and culture agent that all parts integrated to create his /her quality of life. Hence, this study will assess the bio- psychosocial and cultural aspects of clients complaining of sickle cell anemia and thalassemia for further `better management. To perform this study researcher review literature to be acknowledged with is studies conducted in Saudi Arabia this perspective. The results of the search were conclude than no researches were done as regards this problem area.

### **Aim of the study is to:**

The aim of this study is to assess bio psychosocial and cultural aspects of Saudi clients of complain of sickle cell anemia and thalassemia.

### **Research questions:**

- 1- What are bio- psychosocial aspects clients complaining of sickle cell anemia and thalassemia?
- 2- What are cultural aspects clients complaining of sickle cell anemia and thalassemia?

### **Operational definitions:**

#### **1- Biological aspects:**

Physical assessment of clients includes genotype, signs & symptoms of diseases, medical complication, and treatment.

#### **2- Psychological aspect:**

Assessment of clients including emotional felling and psychological problems ex (stress, depression,, and anxiety) and coping behaviors.

#### **3- Social aspects:**

Assessment of clients includes attitude, personal relationship for example: (family, friends, community and employment status, education level and discrimination).and helping needs from any agency to available that for example: (housing, medical care, foods, transportations, and hygiene products)

#### **4- Culture aspects:**

Assessment of clients of culture values, health beliefs, traditions, and spiritual religious management.

#### **Conceptual framework:**

Biopsychosocial (BPS) approach, originally proposed by Engel in (1977) cited from (Meyer, 2010) took a comprehensive perspective to integrating the psychological, biological, and sociocultural influences on human development and functioning. This approach had been very useful by the health care providers around the globe in caring patients experiencing mental and physical problems (Meyer, 2010).

Bio-psycho-social framework has; applied to care patient. After Proved that bio-psycho-social framework has developed over time, but actual application of this framework in patient care fullness has been very slowly. In the field of psychology, suggested that the application of bio-psycho-social framework has yet to be used to its great prospectively and should be considered in emerging theories of clinical practice and health psychology. Research has identified biological, psychological and social (environmental)(Marsac, M. L.et al ,2014).

The essential measures of the chronic pain BPS model are psychological, biological, and social developments. The factors of Biological and psychological contain to central and peripheral processes and genetic tendencies. They are subjective by efferent and afferent feedback between systems of biological and psychological, which in turn impact the immune system. Social reasons relate with the system of biological and psychological and contain to the following elements: the daily living activities which is(ADL), interpersonal, stressors of environment, family, social support/isolation, social expectations, cultural, medico-legal/ insurance matters, previous treatment experiences, and work history. See the figure (1) (Haywood, C.et al, 2014).

## **MATERIAL& METHODS**

### **Study Design:**

The study adopts a quantitative, cross sectional design.

### **Study Setting:**

The study was conducted in two places at Riyadh city as following:

- 1- Prince Sultan Riyadh Military Medical City (PSRMMC) affiliated to ministry of defence & aviation, (PSRMMC) is one of the hospitals serving the ministry of defence personal and it was established 1979. The largest hospital in the Riyadh after King Faisal Hospital treatment blood disorder and bone marrow transplantation especially all clients complain of sickle cell and thalassemia.
- 2- King Khalid University Hospital (KKUH) is located in Riyadh and its part of the king Saud University. The largest educational hospital in Riyadh and receives a large number of cases of patients with blood disorder especially complain of sickle cell and thalassemia.

### **Subjects:**

The sample type was convenience. total number of the study sample was 133 Saudi patients, who enrolled to these previous two hospitals within 3 months selected according to the standards, rules for sample size calculation. By Richard A. Geiger 1983.

The number of patients in each hospital during the time data collection is 200 hundred (who agree to participate the study) is 133, therefore, the sample represent (66.5%) of the patients in both hospitals.

### **Criteria for subject's recruitments:**

#### **- Inclusive criteria;**

- 1- Saudi nationality
- 2- Diagnosis with sickle cell and thalassemia diseases.
- 3- Age group for less than 20 years to more than 35 years.
- 4- Who agree to participate in the study.

### **Tool of the study:**

#### **A Structured Self – Administered Questionnaire:**

A Structured Self – Administered Questionnaire sheet was developed by the researcher after reviewing literature to understand the subject and assess people with sickle cell anemia and thalassemia. It included six parts as the following:

**Part one:** The socio-demographic section will cover information about their age, sex, and marital status. As well as both level of education & occupation and medical diagnosis. Demographic and Clinical data were collected from records from the previous settings mentioned above.

**Part two:** medical history aspect for example, illness diagnosis, how many times admitted in hospital, length stays last time in the hospital, and Current health condition.

**Part three:** biological aspects for example signs and symptoms of diseases, and complication.

**Part four:** psychological aspect for examples, anxiety, depression, self-blame and hate, worry and emotional instability.

**Part five:** social aspects for examples, attitude toward illness, awareness, work problems, education problems, and social communication.

**Part six:** culture aspects for example, engage in family visits, dealing traditional healer, lasing people, customs and believes and values, religious and spiritual management.

In order to give a clear meaning for the mean scores which will be calculated for scale, the range is calculated for the scale where the range =  $4-1=3$ , by dividing the range by the number of categories (4) resulted  $3/4= 0.75$  which the length of each category of four scales, then the length of the category is added to the lowest grade of the scale which is the number (1). So the first category is produced to be (1-1.75) by adding the length of the highest limit for the category to produce the second category and so on for the rest of the categories.

### **Statistical techniques:**

All questions in the questionnaire were coded and entered into the computer through statistical package for social sciences (SPSS) version 23. Variables were described using frequency distribution for categorical variables and means with standard deviations for continuous variables and according to the objectives of the study.

### **The following statistical methods used:**

1. Frequencies and percentage for the description of study sample demographic characteristics.
2. Mean and standard deviation to specify the study sample response towards the items of the four scales, and mean and SD used to rank the items based on the point of view of the sample.
3. Pearson's correlation coefficient: to reveal the validity of the internal consistency of the study instrument and to assess correlation between demographic characteristics and bio-psychosocial and cultural aspects.
4. Cronbach's alpha: to measure the reliability of the study instrument.

### **RELIABILITY AND VALIDITY**

#### **- Validity:**

The validity of internal consistency of the questioners was tested using person correlation coefficient between the score of each item in the questionnaire all the coefficients of the items correlation with the Vital / Physical aspects scale are significant at the level of (0.01) and (0.05) which mean that there is internal consistency. Moreover, the correlation between psychological aspects scale and its items, all the statements are significantly correlated with the total score of the scale except 4 items that are not significant, however, the overall factorial structure of the scale is holding. also all items are significantly correlated with the social aspects scale and all the items are significantly correlated with the scale except one item. In addition, correlation between the cultural aspects scale and each items and all items are significant.

### **Face & content validity:**

Face validity for the instrument was established through the comprehensive review of literature in the area related assessment of bio-psychosocial and culture aspects of clients complaining of sickle cell anemia and thalassemia. To establish content validity, the questionnaire was sent to an expert group of ten reviewers (assessors) who are expertise in developing survey studies of HRQOL Knowledge recognizing their research and publication record (eight of reviewers were academic staff from college of nursing, two of consultant hematology from prince sultan military medical city). Minor changes made to the questionnaire based on modification the reviewers comments and feedback.

### **- Reliability**

The reliability of both scales items was tested and the overall reliability of all items were tested using Cronbach's Alpha coefficient. Table (6) show that the biological / Physical aspects is (0.873) which is high and excellent and also the reliability of The psychological aspects scale is excellent (0.916) which is also high and the social aspects scale alpha value is (0.853) which is considered excellent. Moreover, the cultural aspect is almost good (0.741) which near (0.70) which is considered appropriate. Therefore, we can conclude that an item is reliable and could be used in the analysis and in this study.

### **Ethical considerations:**

Prior to conducting the study, written permission was obtained from the college of nursing at king Saud university and the director of prince sultan military medical city and king Saud medical city in Riyadh city. The process of data collection, analysis and reporting was elaborated by the student researcher confidentiality of the information obtained was assured. The name of adult participants were not solicited or written down and were kept anonymous. Informed consent document have been taken and kept in private place.

### **The pilot study**

A pilot study was carried out on twenty (20% of the total sample) to examine the clarity and reliability of questionnaire and to estimate the time needed each patient to fill out the questionnaire and modifications were done accordingly. Those participants were not included in the study. Data collection was conducted in clinic and adult ward located in prince sultan bone marrow transplant unit and King Saud medical city.

### **Work procedure:**

The researcher follows the consequent steps in processing the actual work-study:

- 1- Administrative approval** for conducting the study was obtained by sending an official letter from the vice dean from academic affairs in the nursing college at King Saud university to the director of prince sultan military medical city and King Saud medical city. The approval was obtained after explaining the purpose and method of the study to them. (The official letter number Appendix B).
- 2-** Develop the tool by student researcher of the review literature the reliability of all scales was tested using Cronbach's Alpha coefficient. Face validity and reliability of the tool were established through jury member and statistical analysis.
- 3-** Pilot study done in order to test the research conduction visibility applicability.
- 4-** Ethical aspects of research followed.
- 5-** Data collect done by the student researcher; questionnaire distributed by a Structured Self – Administered Questionnaire after obtain the permission written consent was obtained after acknowledging the subject about to aim & all issues related to the research study before start participating in this research.
- 6-** Collection data for the present was done during the period from (onset 20 October 2016 to the 20 January 2017) the average time spent for collection data for each participant was approximately 20 minutes.
- 7-** Statistical analysis was done as mentioned before.

## RESULTS:

### Socio-demographic characteristics:

Table 1:

Gender	Frequency	Percent
Male	63	47.4
Female	70	52.6
<b>Total</b>	133	100
Age	Frequency	Percent
less than 20 – 25	51	38.3
more than 25 – 30	34	25.6
more than 30 – 35	37	27.8
more than 35 – 40	11	8.3
<b>Total</b>	133	100
Marital status	Frequency	Percent
Married	48	36.1
Single	77	57.9
Divorced	7	5.3
Widow	1	0.8
<b>Total</b>	133	100
Job status	Frequency	Percent
permanent work	47	35.3
temporary work	14	10.5
not working	63	47.4
Retired	1	0.8
Seasonal	8	6
<b>Total</b>	133	100
illness diagnosis	Frequency	Percent
sickle cell anemia	88	66.2
Thalassemia	15	11.3
sickle cell anemia and Thalassemia	30	22.6
<b>Total</b>	133	100
Length of hospital stay	Frequency	Percent
1-3 days	50	37.6
4-7 days	42	31.6
more than 1 week	33	24.8
Missing(no answer)	8	6
<b>Total</b>	١٣٣	100

**Table 1-Socio-demographic characteristics :**

(47.4%) of the sampled client are males and (52.6%) are females.  
(38.3%) of the sample were in the age group (less than 20-25) then (27.8%) comes next for which their age group is (more than 30-35). Moreover, find that only (8.3%) of sample were in the age group (more than 35-40) which is considered the lowest age group. (57.9%) of the client social status is single, and (36.1%) were married; only (5.3%) are divorced.  
The job status of the client and find that (47.4%) of the sample does not work which represent the majority of the sample and (35.3%) have a permanent work.  
the illness diagnosis is for the client and find that (66.2%) of the clients are diagnosed with sickle cell anemia and (22.6%) are diagnosed with sickle cell anemia and Mediterranean anemia or Thalassemia, only (11.3%) have Thalassemia.  
(24.8%) of the sample stayed in hospital for more than 1 week and (31.6%) stayed for 4-7 days, and (37.6%) stayed between 1 to 3 days.

**The research has two questions to be answered:**

- 1- What are bio- psychosocial aspects of people with sickle cell anemia and thalassemia?
- 2- What are cultural aspects of people with sickle cell anemia and thalassemia?

The first question in the study that needs to answer is to what are bio- psychosocial aspects of people with sickle cell anemia and thalassemia. In order to be able to answer the question we need to analyse the patient bio- psychosocial aspects scales in the questionnaire, which include 3 scales biological / Physical aspects, psychological aspects and the social aspects. Frequencies and percentages will be used to explore the answer, mean, and standard deviation to measure the impact of each item.

**Table (2) Periodic biological \ physical examination aspects:**

Item	not-applicable	Rare	sometimes	Often	always	Mean	Standard Deviation	Rank
Urine	15.00%	24.80%	28.60%	15.00%	16.50%	1.932	1.292	3
Blood	0.00%	0.00%	15.00%	21.10%	63.90%	3.489	0.745	1
Chest scan	9.00%	18.00%	27.80%	30.10%	15.00%	2.241	1.182	2
<b>Periodic examination</b>						<b>2.554</b>	<b>1.073</b>	

In addition, from looking at table (2) and going into biological / Physical aspects and statements are ranked within each sub-scale to show which statement have more agreement than the other.

In Sub-Scale Periodic examination, the overall mean is (2.554) which fall into the often category and Statement “blood” examination had the highest mean (3.489) which indicate that this item is the most common to happen for client, then comes in second the statement “Chest scan” with mean (2.241). Then comes in third statements “Urine” with mean (1.932).

**Table (3) physical complications:**

Item	not-applicable	rare	sometimes	Often	always	Mean	Standard Deviation	Rank
acute chest syndrome	38.30%	8.30%	16.50%	22.60%	14.30%	1.662	1.522	1
Heart Failure	57.10%	9.00%	24.10%	6.80%	3.00%	0.895	1.163	4

chronic renal failure	58.60%	15.80 %	12.80 %	9.00%	3.80%	0.83 5	1.182	7
brain stroke	66.20%	12.00 %	10.50 %	6.00%	5.30%	0.72 2	1.189	9
The composition of Cholelithiasis	39.10%	12.00 %	18.80 %	15.00 %	15.00 %	1.54 9	1.5	3
pulmonary hypertension	55.60%	18.00 %	15.00 %	9.80%	1.50%	0.83 5	1.102	6
hip joint osteomrelitis	37.60%	15.00 %	14.30 %	12.80 %	20.30 %	1.63 2	1.574	2
Chronic leg ulcer	54.90%	19.50 %	13.50 %	8.30%	3.80%	0.86 5	1.16	5
Retinopathy	57.90%	22.60 %	12.00 %	4.50%	3.00%	0.72 2	1.04	8
<b>Total overall</b>						<b>1.07 9</b>	<b>1.270</b>	

Moreover, Complications the overall mean is (1.07) which fall into the rarely category and Statement “acute chest syndrome” had the highest mean (1.662) which indicate that this item is the most common to happen for client in this, then comes in second the statement “hip joint osteomrelitis” with mean (1.632). Then comes in third statements “The composition of Cholelithiasis” with mean (1.549). The least happening statements in this sub-scale are “brain stroke” with mean (0.722).

**Table (4) Nutrition of people with sickle cell anemia and thalassemia scale items**

Item	not-applicable	Rare	sometimes	often	always	Mean	Standard Deviation	Rank
	%	%	%	%	%			
Fresh vegetables	0.00%	6.00%	31.60%	30.10%	32.30%	2.887	0.935	3
Fresh Fruits	0.80%	6.80%	34.60%	37.60%	20.30%	2.699	0.896	7
Cooked vegetables such as potatoes, zucchini, carrots, etc.)	3.00%	9.80%	22.60%	32.30%	32.30%	2.812	1.088	5
Red meat	1.50%	3.80%	32.30%	35.30%	27.10%	2.827	0.925	4
Chicken	0.00%	1.50%	19.50%	21.10%	57.90%	3.353	0.846	1
grains of all kinds	0.80%	12.00%	24.80%	36.10%	26.30%	2.752	1.003	6
fried foods (such as fish, potatoes, etc.)	0.00%	3.80%	18.00%	37.60%	40.60%	3.15	0.848	2
Fast food	1.50%	12.80%	27.80%	34.60%	23.30%	2.654	1.023	8
drink water 3 liters and more every day	4.50%	10.50%	32.30%	24.10%	28.60%	2.617	1.14	9
drink liquid for example (juice, and milk, etc...)from 2 liters every day	3.00%	13.50%	27.80%	30.80%	24.80%	2.609	1.093	10
<b>Total</b>						<b>2.836</b>	<b>0.9797</b>	

Nutrition the overall mean is (2.836) which fall into the often category and Statement “chicken” had the highest mean (3.353) which indicate that this item is the most common to happen for client in this sub-scale, then comes in second the statement “fried foods (such as fish, potatoes, etc.)” with mean (3.15). Then comes in third statements “Fresh vegetables” with mean (2.887). The least happening statements in this sub-scale are “arts, (drink liquid for example (juice, and milk, etc...) from 2 liters every day)” with mean (2.609).

**Table (5) feelings about sickness aspects**

Item	not-applicable	Rare	sometimes	often	always	Mean	Standard Deviation	Rank
Anxiety	18.00%	12.00%	15.80%	29.30%	24.80%	2.308	1.43	4
Sadness	21.80%	7.50%	30.80%	18.00%	21.80%	2.105	1.42	5
Self heaterate	43.60%	12.00%	17.30%	19.50%	7.50%	1.353	1.40	8
self-blame	45.10%	7.50%	13.50%	17.30%	16.50%	1.526	1.58	8
Anger	34.60%	14.30%	20.30%	20.30%	10.50%	1.579	1.41	6
Satisfaction	7.50%	5.30%	19.50%	22.60%	45.10%	2.925	1.24	2
Contentment	7.50%	7.50%	19.50%	19.50%	45.90%	2.887	1.28	3
thanks God	4.50%	2.30%	12.00%	15.80%	65.40%	3.353	1.07	1
<b>Total</b>						<b>2.2545</b>	<b>1.354</b>	

In Describe feelings about sickness, the overall mean is (2.25) which fall into the sometimes category and Statement “thanks God” had the highest mean (3.353) which indicate that this item is the most common to happen for client, then comes in second the statement “contentment” with mean (2.887). Then comes in third statements “satisfaction” with mean (2.92). The least happening statements in this sub-scale are “self-blame” with mean (1.526).

**Table (6) signs and symptoms of emotional problems aspects**

Item	not-applicable	rare	Sometimes	often	always	Mean	Standard Deviation
Frustration	25.60%	12.00%	19.50%	26.30%	16.50%	1.962	1.44
lack of interest	24.80%	15.80%	30.10%	19.50%	9.80%	1.737	1.30
No sense of humor	30.80%	14.30%	20.30%	31.60%	3.00%	1.617	1.30
Easily Excitable	9.80%	9.80%	25.60%	22.60%	32.30%	2.579	1.30
Impulsive	15.00%	12.00%	29.30%	24.10%	19.50%	2.211	1.31

Emotional confusion	18.80%	12.00 %	30.80%	18.80%	19.50%	2.083	1.36
excessive preoccupation	23.30%	15.80 %	24.80%	23.30%	12.80%	1.865	1.35
Helplessness	34.60%	12.00 %	28.60%	10.50%	14.30%	1.579	1.42
<b>Total</b>						<b>1.954</b>	<b>1.346</b>

In addition, as regards signs and symptoms emotional problems the overall mean is (1.954) which fall into the sometimes category and Statement “ easily excitable” had the highest mean (2.579) which indicate that this item is the most common to happen for client in this sub-scale, then comes in second the statement “impulsive” with mean (2.211). Then comes in third statements “Emotional confusion” with mean (2.083). The least happening statements in this sub-scale are “helplessness” with mean (1.579).

**Table (7) cultural aspects of people with sickle cell anemia and thalassemia scale items**

Item	not-applicable	Rare	Sometimes	Often	always	Mean	Standard Deviation
Do you regularly pray in its specific times?	0.80%	1.50%	14.30%	36.10%	47.40%	3.278	0.82
Do you read the holy Quran or listen to it?	0.80%	1.50%	30.10%	30.10%	37.60%	3.023	0.9
Do you follow the traditions of the prophet Mohamed (S) like (praise, thanksgiving and cheer)?	0.80%	3.00%	18.00%	24.80%	53.40%	3.271	0.914
Do you attend any religious lectures or seminars?	10.50%	21.10%	37.60%	16.50%	14.30%	2.03	1.174
Do you listen to any religious lectures or seminars?	8.30%	18.00%	33.80%	21.80%	18.00%	2.233	1.186
Are you registered in memorizing the holy Quran and narrating it in the correct way?	42.10%	17.30%	13.50%	10.50%	16.50%	1.421	1.519

Do you think that this sickness is not hereditary and it is because king of envy or magic?	51.10%	6.80%	18.80%	12.80%	10.50%	1.248	1.453
Do you think that this sickness can be treated by the Roquia and does not need any doctor?	45.10%	9.80%	16.50%	21.10%	7.50%	1.361	1.421
Do you think that the religious beliefs play a positive role in the adaptation strategy with this sickness?	15.80%	6.80%	22.60%	20.30%	34.60%	2.511	1.428
Do you think that it is obligatory to marry from the relatives even if you know that he is sick with sickle cell anemia or Mediterranean anemia?	48.10%	14.30%	17.30%	13.50%	6.80%	1.165	1.338
<b>Overall</b>						<b>2.154 1</b>	<b>1.2153</b>

Cultural aspects of people with sickle cell anemia and thalassemia scale items, the overall mean is (2.15) which indicate that the cultural aspects of people with sickle cell anemia and thalassemia are sometimes to happen as the overall mean fall in the category sometimes. The highest statement is “Do you regularly pray in its specific times” with mean (3.278) , then second item “Do you follow the traditions of the prophet Mohamed (S) like (praise, thanksgiving and cheer)” with mean (3.271) , and the least impact item is “Do you think that it is obligatory to marry from the relatives even if you know that he is sick with sickle cell anemia or Mediterranean anemia” with mean (1.165) which is rarely to happen.

### Discussion

Demographic characteristic of the studied result of this present study showed that 38.3% of subject less than 20 years old, males represent 47.4% and females were counted to 52.6 % . Also 57.9 % were single and the rest between married and divorced. The job or employment status the highest number of employed was 51%, not working 47.4%, and least number of retired was 0.8%.

Similar characteristics was pointed by Anie K. A. et al (2010). Psychosocial impact of sickle cell diseases in Nigeria study the age group from less than 14 to 44 years the highest number of her subject were 38% and least frequency among studied population were above 35 to 40 limited to 5%. Also for gender in same study present is male 48% and female 52%. And employed was 23 % and lowest retired 0 % ( Anie K. A. et al, 2010).

Another study found that sixty-four percent were employed at the time of assessment (Edwards, C. Let al, 2014).

In this present research results shows that studied clients currently live with husband/ wife accounted to (30.8%). (30.1%) are lives with family, in addition, (33.8%) living with father/mother/brothers/sisters. only (3%) are living alone. As regards education level (38.3%) have university degree and (31.6%) of patients have secondary and intermediate schools (15%).

In concordance with the previous characteristics study by Matthie N. Jenerette C. McMillan S (2015) in Role of Self-Care in Sickle Cell Disease was conducted female were 61.2%,and male were 38.8% ,education in 13-16 age group 24.3% and employment status was unemployed 35.0%, disabled 33%, and employed 32%.also living status was living with family were 73.8%,live alone were 17.5%,and share house with friends were 8.7%(Matthie, N.et al, 2015).

However, a national study by Mohammed *D.et al. (2013) exhibit that .In* Western Saudi Arabia Two-thirds (60.9%) 28 were males, female 18(39.1%) only 21.7% of the patients in our study population were of Saudi nationality; the rest were of various nationalities78.3%.also Level of education was highest number Primary 26 (56.5%) and lowest number was Secondary 1 (2.2%).(Ayoub, M. D., Radi, S. A.et al,2013).

In this present study, for how many times the clients stayed in the hospital (22.6%) of the sample never stayed at hospital ,(32.3%) stayed two times, also (15.8%) stayed 3 times and ,only (13.5%) stayed one and 4 times and more.

The previous results similar to the study to the following study number hospitalization previous year the patient none hospitalized 20.4% and between one and two times hospitalized was 42%, lowest number between 3times until eight times (Adegbola, M.2011).

Another study search on Religious coping and the Use of Prayer in Children with Sickle Cell Disease according to Cotton S. et al (2015). Number of hospitalization in past year zero hospitalization were 47%, one hospitalization 37%, tow hospitalization 11%, and three hospitalization 5% (Cotton, S., Grosseohme, D.et al, 2015).

The result of this present study show that the statement of how long stay last time in the hospital found that highest number (37.6%) stayed between one to three days, then (31.6%) stayed for 4-7 days, and lowest number (24.8%) of the sample stayed for more than one week.

As regard length of stay in hospital highest number of one to three days 65%, then four to six days 17%, and lowest were from seven to 20 days 5% in a similar study (Matthie N. et al, 2015).

In this study discussion of results ought to find solution of main three questions. The first question to be replied in this study was; what are biopsychosocial aspects of people with sickle cell anemia and thalassemia?

From this present study, as regard physical/biological aspect of Periodic examination, the overall mean is (2.554) which fall into the often category and Statement “blood” examination had the highest mean (3.489) which indicate that this item is the most common to happen for clients, then comes in second the statement “Chest scan” with mean (2.241). Then comes in third statements “Urine” with mean (1.932).

This may be because chest pain is sometimes confusing for the clients with other symptoms According to Novelli E et al, (2016). Acute Chest Syndrome is occasionally misdiagnosed as aspiration Pneumonia.

The members of this cohort had repeated physical examinations and laboratory assessments (blood and urine) at regular intervals, and clinical events for each patient were documented using standard definitions and data collection forms.

Seven percent of our Hb SS population experienced a CVA before the MR examination (Moser, F. G., Miller, S. T. et al, 1996).

According to McClishDet al,( 2017) Comorbidity, Pain, Utilization, and Psychosocial Outcomes in Older versus Younger Sickle Cell Adults collected laboratory data via blood and urine samples.

The present study found that signs and symptoms of the disease the Statement “Bone and joint pain” had the highest mean (3.105) which indicated that the most troubles some signs and symptoms common to happen this client group, then comes in second the statement “fatigue by less effort” with mean (2.767). Then comes in third statements “dry lips and mouth” with mean (2.639). painful crises are one of the most troubles some symptom for all clients SCD (Amaral, J. L. et al, 2016).

According to McClishDet al, (2017).other complain was found as comorbidity, Pain, Utilization, and Psychosocial Outcomes in Older versus Younger Sickle Cell Adults: The PiSCES Project the physical symptoms (like headaches, dizziness, heart pounding, sleep problems, nausea, bowel function issues, etc.) that account for more than 90% of symptoms seen in primary care (exclusive of upper respiratory symptoms such as cough).

In this present study result of male complain about priapism mean is (1.458).this acute pain is typically felt in the bones; the small bones of fingers and toes in children (dactylitis), and the long bones of the limbs or in the trunk and chest in clients. Acute pain in SCD may also be due to priapism (prolonged painful erection) or inflammation of the gall bladder (Howard, J. et al.2009).

The Complications acknowledged by people with sickle cell anemia and thalassemia Statement “acute chest syndrome” had the highest mean (1.662) ,then comes in second the statement “ hip joint osteomrelitis” with mean (1.632). Then comes in third statements “The composition of Cholelithiasis with mean (1.549). The least happening statements are “brain stroke” with mean (0.722).

In contrast with the results of this present study a study on Sickle cell disease-related organ damage occurs irrespective of pain rate: implications for clinical practice according to Eduard J. et al, (2008).

It showed that High Prevalence cholelithiasis 66% in sickle cell anemia than thalassemia, acute chest syndrome and pulmonary hypertension were 32% , Retinopathy were 24%, Priapism in male were 21% ,and the least stroke were 11% .(van Beers, E. J.et al,2008).

Result of this present study complication with client's pulmonary hypertension, Retinopathy, Heart Failure, and chronic leg ulcer show the table (22). In concordance a study of Hemoglobin SC disease complications: a clinical study of 179 cases by Lionnet F et al, (2012). Prevalence of hospitalized painful vaso-occlusive crisis, acute chest syndrome and priapism was 36%, 20% and 20%, respectively. The most common chronic organ complications were retinopathy and sensor neuralotological disorders in 70% and 29% of cases. Pulmonary hypertension, strokes and leg ulcers was rather low (13%, 4% and 1%, respectively).

Chronic pain is also a common feature of SCD, especially from late adolescence onwards, and its incidence increases with age. This is often due to a vascular necrosis (death of the bone owing to vaso-occlusion) and typically affects the hip and shoulder joints, although it may affect other bones. Chronic pain may also be due to leg ulcers or chronic osteomyelitis (Howard, J.et al,2009).

Emotional problems the overall mean is (1.954) which fall into the sometimes category and Statement “ easily excitable” had the highest mean (2.579) which indicate that this item is the most common to happen for patient, then comes in second the statement “impulsive” with mean (2.211). Then comes in third statements “Emotional confusion” with mean (2.083). The least happening statements in this sub-scale are “helplessness” with mean (1.579).

Anie K et al (2010) in Nigeria .Adult Self-hate 21 (8%) Depressive feeling 122 (44%).Anxiety feelings 33(13%). All emotions 25 (10%). None 62 (25%). 170 patient aged 11-20 years, also noted that about 88% were worried and 55% has depressive thought about their condition. People with sickle cell dieses commonly report low self –esteem and feelings of hopelessness as result of frequent pain, hospitalization. The present research target populations also have self haterate, self-blame anger, and sadness show the (table 27).

As regards psychological problems in the study overall mean is (1.518) which fall into the rarely category and Statement “intense anger” had the highest mean (2.158) which indicate that this item is the most common to happen for patient in this sub-scale, then comes in second the statement “excessive anxiety” with mean (2.09). Then comes in third statements “easily provocation” with mean (1.94). The least happening statements in this sub-scale are “previous attempt to suicide” with mean (0.767).

Burlew k et al,(2000) found through his study factors that influence adolescent adaptation to sickle cell disease.26% of the sample reported score on the beck depression inventory indicating mild to severe level of depressive symptoms. In study from other perspectives integrate emotional and psychological problems of sickle cell disease and thalassemia according to (Edwards, C. L.et al, 2014). Twenty-nine percent of patients reported that they had experienced “Anxiety,” and 36% indicated that they had experienced “Depression” in the 30 days prior to assessment.

A national study in King Faisal hospital about depression in Sickle-Cell Disease patients in the Eastern Province Zahra Aljumah, et al, (2016). A thirty-eight point nine (38.9%) of the sample were not having depression, (23.2%) with mild depression, (9%) with borderline clinical depression, (20.6%) with Moderate depression,(6.8%) with Severe depression, and (1.6%) with Extreme depression.(Aljumah, Z., Ali, S.et al ,2016).

The second question in the study that needs to answer is what are cultural aspects of people with sickle cell anemia and thalassemia. In order to be able to answer this question it is needed to analyses the patient cultural aspects. It was obvious in this study that the highest statement “Do you regularly pray in its specific times” was ranked as first statement then second item “Do you follow the traditions of the prophet Mohamed (S) like (praise, thanks giving and cheer)” with mean (3.271) , and the least impact item is “Do you think that it is obligatory to marry from the relatives even if you know that he is sick with sickle cell anemia or Mediterranean anemia” with mean (1.165) which is rarely to happen.

Beliefs can be influenced by culture for example, it has been suggested that Nigerians have tried religious healing (prayer) as an alternative approach or in addition to routine medical treatment. Also such beliefs lead to negative perceptions and attitudes about SCD (K. A. Anie ET AL, 2010).

Taylor, L. E. V. et al. (2013) Biopsychosocial-Spiritual Model of Chronic Pain in Adults with Sickle Cell Disease. Reported that nearly 70% of the participants found religion to be very important and nearly 50% performed private religious/spiritual activities (e.g., prayer) at least daily.

Another study Religious/Spiritual Coping in Adolescents with Sickle Cell Disease according to Cotton S. et al, (2010). Twenty-four (64%) adolescents prayed at least once a week and 19 (51%) reported attending religious services at least once a week. Adolescents reported praying once or more daily, 9 (26%) prayed once to a few times a week, and 13 (37%) had either never prayed or had prayed only once for symptom management.

Another study it is in Saudi Arabia Marked regional variations in the prevalence of sickle cell disease and b-thalassemia Findings from the premarital screening and genetic counseling program according to Memish Z, Owaidah T, and Saedi M. (2011). It is difficult to explain regional differences in sickle cell disease and b-thalassemia in SA. Certain cultural factors in SA may contribute to the high prevalence of both diseases. These include the high frequency of consanguineous marriages (exceeding 55%) and the large family size. Regional variations in the consanguinity rates in SA were reported with conflicting results. Some published data suggested that the prevalence of first degree consanguinity is highest in the Eastern region (40.9%) and lowest in the Northern region (17.9%).

### **Conclusion:**

It is obvious that there is relationship between frequency of hospitalization and biopsychosocial aspects of clients the most common coping culture patterns among the studied subject were religious and spiritual (praying and thanks god).

the most important relations in this study were affiliated to psychological aspects of the studied clients further more there is a significant relation between psychological aspect and demographic social aspect "marital status".

### **Recommendation:**

- Further researches should be elicited to integrate, acknowledge and explore more aspects as regard biopsychosocial and culture assessment of sickle cell and thalassemia clients.
- Future research is needed to further the understanding of the impact of QOL in adults with SCD.

### **Strengths and limitations of the study**

Among the first strength this is the first trial nursing study for the assessment client from holistic approach.

### **Limitations:**

Number of participant is limited so; student researcher could not generalize also, because sample is not representative.

## References

- Anie, K. A., Egunjobi, F. E., & Akinyanju, O. O. (2010). Psychosocial impact of sickle cell disorder: perspectives from a Nigerian setting. *Globalization and health*, 6(2), 1-6.
- Ayoub, M. D., Radi, S. A., Azab, A. M., Abulaban, A. A., Balkhoyor, A. H., Seif-eleslam, W. B., ... & Kari, J. A. (2013). Quality of life among children with beta-thalassemia major treated in Western Saudi Arabia. *Saudi medical journal*, 34(12), 1281-1286.
- Adegbola, M. (2011). Spirituality, self-efficacy, and quality of life among adults with sickle cell disease. *Southern online journal of nursing research*, 11(1).
- Amaral, J. L., Almeida, N. A., Santos, P. S., de Oliveira, P. P., & Lanza, F. M. (2016). Socio-demographic, economic and health profile of adults with sickle-cell disease. *Northeast Network Nursing Journal*, 16(3).
- Aljumah, Z., Ali, S. I., Al-Saleem, M., Almogarab, K., Alghadeer, F., & AlEsa, F. (2016). Depression in Sickle-Cell Disease patients in the Eastern Province.
- Cotton, S., Grosseohme, D., & McGrady, M. E. (2015). Religious coping and the use of prayer in children with sickle cell disease. *Pediatric blood & cancer*, 58(2), 244-249.
- Crosby, L. E., Quinn, C. T., & Kalinyak, K. A. (2015). A biopsychosocial model for the management of patients with sickle-cell disease transitioning to adult medical care. *Advances in therapy*, 32(4), 293-305.
- Daniel, L. C., Li, Y., Smith, K., Tarazi, R., Robinson, M. R., Patterson, C. A., & Barakat, L. P. (2015). Lessons learned from a randomized controlled trial of a family-based intervention to promote school functioning for school-age children with sickle cell disease. *Journal of pediatric psychology*, 40(10), 1085-1094.
- Dwairy, M. (2009). Culture analysis and metaphor psychotherapy with Arab-Muslim clients. *Journal of Clinical Psychology*, 65(2), 199-209.
- Ezenwa, M. O., Yao, Y., Molokie, R. E., Wang, Z. J., Mandernach, M. W., Suarez, M. L., & Wilkie, D. J. (2016). Coping with Pain in the Face of Healthcare Injustice in Patients with Sickle Cell Disease. *Journal of immigrant and minority health*, 1-8.

- Edwards, C. L., Killough, A., Wood, M., Doyle, T., Feliu, M., Barker, C. S., ... & O'Garra, K. G. N. (2014). Emotional reactions to pain predict psychological distress in adult patients with Sickle Cell Disease (SCD). *The International Journal of Psychiatry in Medicine*, 47(1), 1-16.
- He, Y., Wilkie, D. J., Nazari, J., Wang, R., Messing, R. O., DeSimone, J. & Wang, Z. J. (2016). PKC $\delta$ -targeted intervention relieves chronic pain in a murine sickle cell disease model. *The Journal of clinical investigation*, 126(8), 3053-3057.
- Hensler, M., Wolfe, K., Lebensburger, J., Nieman, J., Barnes, M., Nolan, W. & Madan-Swain, A. (2014). Social skills and executive function among youth with sickle cell disease: A preliminary investigation. *Journal of pediatric psychology*, 39(5), 493-500.
- Haywood, C., Diener-West, M., Strouse, J., Carroll, C. P., Bediako, S., Lanzkron, S., ... & IMPORT Investigators. (2014). Perceived discrimination in health care is associated with a greater burden of pain in sickle cell disease. *Journal of pain and symptom management*, 48(5), 934-943.
- Howard, J., Thomas, V. J., & Rawle, H. M. (2009). Pain management and quality of life in sickle cell disease. *Expert review of pharmacoeconomics & outcomes research*, 9(4), 347-352.
- Imhonde, H. O., Ndom, R. J. E., & Ehon, A. (2013). Social-support, self-esteem and depression as determinants of quality of life among sickle cell patients. *IFE Psychologia: An International Journal*, 21(1), 101-113.
- Lionnet, F., Hammoudi, N., Stojanovic, K. S., Avellino, V., Grateau, G., Girot, R., & Haymann, J. P. (2012). Hemoglobin SC disease complications: a clinical study of 179 cases. *haematologica*, 97(8), 1136-1141.
- Memish, Z. A., Owaidah, T. M., & Saedi, M. Y. (2011). Marked regional variations in the prevalence of sickle cell disease and  $\beta$ -thalassemia in Saudi Arabia: Findings from the premarital screening and genetic counseling program. *Journal of epidemiology and global health*, 1(1), 61-68.
- Mallari, M. S. N., Grace, M., & Joseph, D. (2016). Ethical Frameworks for Decision-Making in Nursing Practice and Research: An Integrative Review.

- Marsac, M. L., Kassam-Adams, N., Delahanty, D. L., Widaman, K. F., & Barakat, L. P. (2014). Posttraumatic stress following acute medical trauma in children: A proposed model of bio-psycho-social processes during the peri-trauma period. *Clinical child and family psychology review*, 17(4), 399-411.
- Matthie, N., Jenerette, C., & McMillan, S. (2015). Role of self-care in sickle cell disease. *Pain Management Nursing*, 16(3), 257-266.
- Moser, F. G., Miller, S. T., Bello, J. A., Pegelow, C. H., Zimmerman, R. A., Wang, W. C., & Kinney, T. R. (1996). The spectrum of brain MR abnormalities in sickle-cell disease: a report from the Cooperative Study of Sickle Cell Disease. *American Journal of Neuroradiology*, 17(5), 965-972.
- McClish, D. K., Smith, W. R., Levenson, J. L., Aisiku, I. P., Roberts, J. D., Roseff, S. D., & Bovbjerg, V. E. (2017). Comorbidity, Pain, Utilization, and Psychosocial Outcomes in Older versus Younger Sickle Cell Adults: The PiSCES Project. *BioMed Research International*, 2017.
- Novelli, E. M., & Gladwin, M. T. (2016). Crises in sickle cell disease. *CHEST Journal*, 149(4), 1082-1093.
- Okpala, I., Thomas, V., Westerdale, N., Jegede, T., Raj, K., Daley, S., & Abbs, I. (2002). The comprehensive care of sickle cell disease. *European journal of haematology*, 68(3), 157-162.
- Pettersson, M., Hedström, M., & Höglund, A. T. (2014). Striving for good nursing care: Nurses' experiences of do not resuscitate orders within oncology and hematology care. *Nursing ethics*, 21(8), 902-915.
- Santrock, J. W. (2007). *A Topical Approach to Human Life-span Development* (3rd Ed.). St. Louis, MO: McGraw-Hill.
- Taylor, L. E. V., Stotts, N. A., Humphreys, J., Treadwell, M. J., & Miaskowski, C. (2013). A biopsychosocial-spiritual model of chronic pain in adults with sickle cell disease. *Pain Management Nursing*, 14(4), 287-301.

- van Beers, E. J., van Tuijn, C. F., Mac Gillavry, M. R., van der Giessen, A., Schnog, J. J. B., Biemond, B. J., & CURAMA Study Group. (2008). Sickle cell disease-related organ damage occurs irrespective of pain rate: implications for clinical practice. *haematologica*, 93(5), 757-760.

- WHO 2017 (<http://www.who.int/mediacentre/factsheets/fs308/en/>)