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Quality Of Life For Children With Sickle Cell Anemia

At Center Of Blood Disease In Basra

Graduation project submitted to the college of Nursing, University of Basra a partial Fulfillment of the Requirements of B.S.C in Nursing Sciences

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الآية الكريمة

بسم الله الرحمن الرحيم

﴿أَمَّنْ هُوَ قَانِتٌ آنَاءَ اللَّيْلِ سَاجِدًا وَقَائِمًا يَحْذَرُ
الْآخِرَةَ وَيَرْجُو رَحْمَةَ رَبِّهِ قُلْ هَلْ يَسْتَوِي الَّذِينَ يَعْلَمُونَ
وَالَّذِينَ لَا يَعْلَمُونَ إِنَّمَا يَتَذَكَّرُ أُولُو الْأَلْبَابِ﴾

صدق الله العلي العظيم سورة الزمر (9)

إهداء

نسير في دروب الحياة، ويبقى من يُسيطر على أذهاننا في كل مسلك نسلكه

صاحب الوجه الطيب، والأفعال الحسنة .

فلم يبخل عليَّ طيلة حياته

(والدي العزيز).

إلى من أُفضِّلها على نفسي، ولِمَ لا؛ فلقد ضحَّت من أجلي

ولم تدَّخر جُهدًا في سبيل إسعادي على الدَّوام

(أُمِّي الحبيبة).

إلى اهلي وأصدقائي، وجميع من وقفوا بجواري وساعدوني بكل ما يملكون، وفي

أصعدة كثيرة

أُقدِّم لكم هذا البحث، وأتمنَّى أن يحوز على رضاكم .

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Abstract:

Background: Sickle cell disease is an inherited blood disorder. Physical health problems include painful vaso-occlusive crises. Children and adolescents with may also experience psychological distress, social isolation and an impaired health-related quality of life.

Methodology: A descriptive research design was carried out in at center of blood diseases in the Basra. The study subjects were made up of a convenience sample of 50 children with Sickle Cell Anemia.

Results: Most of patients within 6-12 years age group 70%, more than half of them were female 56%, most of children were primary school students 28%, family members were six members and more for most families 68%, regarding mothers and fathers education, most of them were primary school education 32%,28% respectively. Most of patients always feel pain or discomfort when do something 44%, most of samples 82% never need help when washing and showering. Half of samples 50% feels physically weak.

Conclusions: Most of patients were within 6-12 years old. More than half of them were male. Most of family members were six and more. Parents' educational level were primary school for both. More than half of samples were from rural area. Most of patients always feel pain or discomfort when do something Most of samples never need help when washing and showering. Half of samples feels physically weak. Most of patients feels always their illness is like any other disease that they can cure. Most of patients feel sad always. More than half of patients have been absent due to illness and treatment.

List of contents

List of Tables

List of Appendices

CHAPTER ONE-:

INTRODUCTION

Chapter One

1.1 Introduction:

Sickle cell disease (SCD) is a chronic, inherited hematological disorder that is associated with life-threatening complications that affect all major systems. Frequent painful crises, infections, acute chest syndrome, priapism, splenic sequestrations stroke, and organ failure are the most common complications affecting children with SCD [1].

Sickle cell disease has many complications that impact all aspects of children's life, which include the physical, psycho-logical, social, and mental. Determining health-related quality of life (HRQOL) provides an understanding of SCD burden on those children[2]. It helps providing information to families, and health care providers regarding the impact of the disease on children with SCD. Measuring HRQOL is considered as an important indicator to evaluate health care interventions and treatments [3]. This in turn, will provide opportunities to identify patients' responses to treatment, and tailor appropriate therapies based on the patients' perspective of their HRQOL[4].

In clinical practice, HRQOL information can be useful in identifying and prioritizing health problems for individual SCD cases as well as facilitates identifying any hidden or unexpected health problems. Thus, it aids to decision-making, and in monitoring the health status of the patients[5]. It was also found that, measuring HRQOL has shown to improve communication between patients and providers as well as create a patient-centered environment. In addition, HRQOL is considered as an important predictor for morbidity and mortality outcomes [1].

Therefore, understanding HRQOL concept and clarifying its theoretical and practical aspects is very important for nursing practice. Concept analysis method will help clarifying the concept and define its meaning that could be clearly understood by pediatric nurses when dealing with children having SCD. Also, analyzing HRQOL concept would lead to the development of disease specific measurement tools for the concept to be utilized specifically for children with SCD. The concept "QOL" is a commonly used concept across different disciplines. Initially, QOL was applied in sociology but later it was applied to other disciplines. Although QOL is used in everyday language, it is viewed as a multifaceted concept[6-9]. QOL and HRQOL have been used inter-changeably and remain vague and unclear concepts. The concept HRQOL referred and used widely in healthcare literature. It is considered as a fundamental concept in health care because one of the nursing goals is to enhance the health outcomes and strive to provide quality of care for the patients. Therefore, focusing on QOL and the issues that might affect it can lead to improve nursing care through recognizing the effect of the diseases, evaluating treatments, and facilitating resource decision[10-12].

Importance of study:

Quality of life has been generally accepted as a multi-dimensional construct, useful for the use of evaluating the effects of a chronic disease on the life of an individual [7,11]. SCD is a chronic illness, requiring application of certain practices and lifestyle adaptations to curb the severity of the disease and avoid crisis, and/or early death. Adolescent stage is marked by the formation of interpersonal relationships, and peer support which actually tends to affect their development. In order to fit in with their cohorts, adolescents with SCD may engage in risky behaviours, such as smoking, drinking hard liquor, and having unprotected sex, behaviours which can lead to depression, and negative self-esteem, and by extension, exacerbate the symptoms of the

illness [5,10], and in effect affect the various domains of the life of the individual.

1.2 Aim of Study:

1. Determine the quality of life for child with sickle cell anemia .
2. To find out relationship between quality of life with specific demographic characteristics.

CHAPTER TWO:-

LITERATURE REVIEW

Chapter Two: Literature Review

2.1 Sickle cell disease (SCD).

Sickle cell disease (SCD) refers to a group of hemoglobinopathies that include mutations in the gene encoding the beta subunit of hemoglobin. The first description of SCA 'like' disorder was provided by Dr. Africanus Horton in his book The Disease of Tropical Climates and their Treatment (1872). However, it was not until 1910 when Dr. James B Herrick and Dr. Ernest Irons reported noticing 'sickle shaped' red cells in a dental student (Walter Clement Noel from Grenada).[13] In 1949, independent reports from Dr. James V Neel and Col. E. A. Beet described the patterns of inheritance in patients with SCD. In the same year, Dr. Linus Pauling described the molecular nature of sickle hemoglobin (HbS) in his paper 'Sickle Cell Anemia Hemoglobin.' Ingram Vernon, in 1956, used a fingerprinting technique to describe the replacement of negatively charged glutamine with neutral valine and validated the findings of Linus Pauling.[14]

Within the umbrella of SCD, many subgroups exist, namely sickle cell anemia (SCA), hemoglobin SC disease (HbSC), and hemoglobin sickle-beta-thalassemia (beta-thalassemia positive or beta-thalassemia negative). Several other minor variants within the group of SCDs also, albeit not as common as the aforementioned varieties. Lastly, it is important to mention the sickle cell trait (HbAS), which carries a heterozygous mutation and seldom presents with any clinical signs or symptoms. SCA is the most common form of SCD with a lifelong affliction for hemolytic anemia requiring blood transfusions, pain crises, and organ damage.[15] Since the first description of the irregular sickle-shaped red blood cells (RBC) more than 100 years ago, our understanding of the disease has evolved tremendously. Recent advances in the field, more so within the last three decades, have led to the alleviation of symptoms for countless patients, especially in high-income countries. In 1984, Platt et al. first reported the use of hydroxyurea in increasing the levels of HbF.[16] Since

then, the treatment of sickle cell has taken to new heights by introducing several new agents (voxelotor, crinzalizumab, L-glutamine), and most recently, gene therapy.

2.1.1 Etiology

Hemoglobin (Hb) is a major protein within the red blood cell (RBC). It is made up of four globin chains, two of which are derived from alpha-globin (locus on chromosome 16) and two from beta-globin (locus on chromosome 11). There are many subtypes of Hb. The most common ones that are found in adults without hemoglobinopathies are listed here:

- HbA1- comprises 2 chains of the alpha-globin and two chains of the beta-globin (a2b2) - This constitutes 95% of the adult hemoglobin.
- HbA2- comprises 2 chains of the alpha-globin and two chains of the delta-globin (a2d2) - This constitutes less than 4% of the adult hemoglobin.
- HbF- comprises 2 chains of the alpha-globin and two chains of the gamma-globin (a2g2) - This Hb is more prevalent in the fetus (due to high oxygen binding affinity that helps in extracting oxygen from maternal circulation).

The sickle cell mutation occurs when negatively charged glutamine is replaced by a neutral valine at the sixth position of the beta-globin chain. The mutation is transmitted via Mendelian genetics and is inherited in an autosomal codominant fashion.[17] A homozygous mutation leads to the severest form of SCD, i.e., SCA- also called HBSS disease. The coinheritance of beta-naught thalassemia and sickle cell mutation leads to HBS-Beta-0 disease, which phenotypically behaves like HBSS disease.

A heterozygous inheritance leads to HbAS. Patients with HbAS are not considered within the spectrum of SCD as most of them never present with

typical symptoms of SCA. They might only be detected during screening procedures conducted during childbirth, blood donation, etc.

Several other compound heterozygotes exist where a single copy of the mutated beta-globin gene is co-inherited with a single copy of another mutated gene. The second most common variant of SCD is the HbSC disease, where the sickle cell gene is coinherited with a single copy of the mutated hemoglobin C gene. HbC is formed when glutamine is replaced by lysine at the sixth position on the beta-globin chain. HbSC disease accounts for 30% of patients in the United States.

2.1.2 Epidemiology

The epidemiological data on SCD is scarce. It is well known that SCD and HbAS are more prevalent in sub-Saharan Africa, where the carrier of HbAS is afforded natural protection against severe Plasmodium falciparum malaria. It is estimated that ~230,000 children were born with SCA, and more than 3.5 million neonates were born with HbAS in sub-Saharan Africa in 2010. an estimated 75% of the SCD related births take place in sub-Saharan Africa. West Africa is home to the largest population of individuals with HbSC disease.[15]

The United States (US) Center for Disease Control (CDC) estimates that approximately 100,000 Americans have SCD. The CDC also estimates that 1 in 13 babies born to African-American parents have sickle cell trait, and 1 in 365 African-Americans have SCD. The estimated ratio of Hispanic-Americans with SCD is 1 in 16,300. Children and adolescents make up to 40% of all the SCD patients in the US. The incidence varies by state and geographical concentration of ethnicities. Besides, the migration within the country and immigration from foreign countries alter the prevalence of SCD and HbAS. This is true for several countries where patients with SCD and SCA are living. Genetic studies in Brazil have also tied the origin of such patients to the slave trade originating from West Africa (Mina Coast and Angola).[18] With the

improvement in technology and ease of international migration, the incidence of SCA is predicted to rise in the future. It is estimated that the annual number of newborns with SCA will exceed 400,000 by the year 2050.

There is also a stark difference in mortality and morbidity in high-income and low-income countries. Adopting vaccination guidelines for children with SCD and intensive screening procedures has sharply reduced the mortality of kids with SCD between 0 to 4 years (68% drop noted for 1999 to 2002 compared to 1983 to 1986). On the other hand, in sub-Saharan Africa, 50 to 90% of children born with SCD will die before their fifth birthday. Improvement in the care afforded in the high-income countries and targeted training of healthcare providers have improved life expectancy. However, it still lags by decades compared to matched non-SCD cohorts (54 versus 76 years - projected life expectancy, and 33 years versus 67 years- quality-adjusted life expectancy).[19]

HbSC disease accounts for 30% of all patients with SCD in the US. As with HbAS, patients with the Hb C trait (heterozygous mutation) also remain asymptomatic for the majority of their lives. Although considered a milder variant of SCD disease, HbSC disease may present with severe morbidities.[12]

2.1.3 Pathophysiology

SCA is characterized by two major components: Hemolysis and vaso-occlusive crises (VOC). The defect in the beta-globin gene makes the sickle hemoglobin (HbS) molecule susceptible to convert into rigid, elongated polymers in a deoxygenated state. The sickling process is cyclical initially, where sickle erythrocytes oscillate between the normal biconcave shape and the abnormal crescent shape (acquired under low oxygen pressure). However, there comes a time when the change becomes irreversible, and the sickle erythrocytes acquire a permanent sickle shape increasing the risk for hemolysis

and VOC. All variants of SCD share the same pathophysiology leading to polymerization of the HbS component.[15]

2.1.4 Prognosis

Most of the survival data in patients with SCA does not factor in the advent of the new medications. The Cooperative Study of Sickle Cell Disease (CSSCD) (between 1978-88) reported the median age of death for women and men as 42 and 48 years, respectively. This study also showed that acute chest syndrome, renal failure, seizures, high leukocyte count, and low level of HbF were associated with an increased risk of early death in patients with SCA.[21] More recent studies have shown that elevated tricuspid regurgitant jet velocity on echocardiography, prolonged QTc interval, pulmonary hypertension, high N-terminal pro-brain natriuretic peptide, history of asthma and/or wheezing, history of end-stage renal disease requiring dialysis, and the severity of hemolysis are independent risk factors towards early death in patients with SCA.[22]

2.2 Sickle Cell Disease Pain in Children

Acute and chronic pain is the common hallmark of SCD, which is a life threatening and incurable condition[23].The lack of healthy red blood cells to carry oxygen throughout the body causes recurring episodes of severe pain that may cause organ damage, serious infections, stroke, tiredness, irritability, jaundice, slow growth, fast heart rate, pale skin color, and delayed puberty. Other complications of SCD are hemolytic anemia, cerebrovascular accidents, vasoocclusions, opthamological complication, and fatigue [24].

Children with SCD experience vaso-occlusive acute pain that occurs more than 5 times a year, and sometimes lasts for up to 3 days [25]. In addition to vaso-occlusive acute pain episodes, chronic pain is also associated with children with SCD. There has been limited discussion on the impact of chronic pain within the SCD pediatric population. Chronic pain is more common in adults and adolescents with SCD than in younger children[26]. The frequency

of SCD chronic pain increases in a child as they mature from childhood into adolescents, and then adults [27]. Evidence shows that vaso-occlusive painful events significantly impact the physical and psychological functioning of children with SCD [28], and children may continue to experience pain at home and functional limitations after receiving medical care [28]. Additionally, Long, Krishnamurthy, and Palemero (2008) noted that children who have chronic SCD encompass the same behavior patterns as children who experience juvenile idiopathic arthritis and headaches. Children with chronic pain often experience sleep disturbance as a common dysfunction [30], and chronic pain is also associated with daytime functioning in school-age children [29].

The goal for treating SCD is to relieve pain; (a) prevent infections, (b) organ (c) damage, stroke, and (d) manage the condition. Mild to moderate pain is regularly treated at home with over the counter medications such as heating pads, rest, and fluids [31]. Fluids assist in preventing dehydration, and acetaminophen (Tylenol) and nonsteroidal anti-inflammatory drugs (Ibuprofen) are provided for mild to moderate pain. Treatments for acute pain are fluids, medicines, and oxygen therapy. Medications and procedures such as hydroxyurea, blood transfusions, and bone marrow transplants are used as alternative solutions to treat severe pain crisis. Hydroxyurea is an oral medication that is used to decrease the occurrence of painful SCD crisis and acute chest pain. Blood transfusions are provided to prevent life threatening conditions such as spleen problems, acute chest syndrome, and stroke. However, not all individuals with SCD need blood transfusions [31].

2.3 Quality of Life of Children with Sickle Cell Disease

With early diagnosis and advanced medical treatment children with SCD are living well into adulthood [32]. Because children with SCD are living well into adulthood it is important to measure their QOL, as this population should have the ability to live independent and productive lives. The QOL a multidimensional concept has several domains and facets that can be used to

measure general QOL and health [33,34]. The information generated for this study is based on the defined domains and facets that can be used for facilitating an understanding of the QOL for an individual with SCD.

CHAPTER THREE:-

METHODOLOGY

Methodology

3.1 Design of the study

The descriptive study was conducted on ““quality of life for children with sickle cell anemia” . The study started from 8 December 2021 to 3 April 2022.

3.2 Setting and sampling of the study

The study was conducted in at center of blood diseases in Basra on non- probability (purposive) sample of 50 children , who selected as convenience type of sampling.

3.3 The study instruments

The studied children were approached personally and interviewed by the researchers with their parents, with a semi - structured pre-tested questionnaire, the items of interest were adopted from the available literature and designed to collect information regarding children.

3.4 Statistical Data Analysis:

Several electronic statistical measures were used by using Statistical Package of Social Sciences (SPSS) version 25, and Microsoft excel (2016) in order to analyze and evaluate the results of the study.

3.5 Descriptive data analysis and Inferential data analysis:

This approach was performed through the determination of:

a. Frequency (f).
b. Percentages:

$$\% \equiv \frac{Frequencies}{sample\ size} x100$$

c. $\overline{X} = \frac{\sum_{i=1}^{k} mifi}{\sum_{i=1}^{k} fi}$

Chi-square (x^2) test:

d. $X^2 = \sum \frac{(O_i - E_i)}{E_i}$

CHAPTER FOUR:-

RESULTS

Chapter Four: Results

Table One: Demographic Data

No.	Item	Frequency	Percentage
1.	**Patient's age (years):**		
	6-12	35	70%
	13-18	15	30%
2.	**Gender:**		
	Male	22	44%
	Female	28	56%
3.	**Child's study:**		
	Preschool	3	%6
	Primary school	34	%28
	Secondary school	13	%26
4.	**Family Members:**		
	Less than 5	16	32%
	6 and more	34	68%
5.	**Mother Education:**		
	Illiterate	7	14%
	Read and write	2	4%
	Primary school	16	32%
	Secondary school	13	26%
	Diploma	6	12%
	College and above	6	12%
6.	**Father Education:**		
	Illiterate	5	10%
	Read and write	1	2%
	Primary school	14	28%
	Secondary school	13	26%
	Diploma	11	22%
	College and above	6	12%
7.	**Residence:**		
	Urban	20	40%
	Rural	30	60%
8.	**Father Occupation:**		
	No work	2	4%
	Worker	27	54%
	Employee	21	42%
9.	**Mother Occupation:**		
	House wife	40	80%
	Worker	7	14%
	Private job	2	4%
	Employee	1	2%

This table showed that most of patients within 6-12 years age group 70%, more than half of them were female 56%, most of children were primary

school students 28%, family members were six members and more for most families 68%, regarding mothers and fathers education, most of them were primary school education 32%,28% respectively,

Table two: Physical Domain

No.	Item	Never		Sometimes		Always	
A	pain and discomfort	F	%	F	%	F	%
1.	I feel pain or discomfort when I do something	10	20%	18	32%	22	44%
2.	Feel the pain in the bones or joints	9	18%	15	30%	26	52%
3.	I feel uncomfortable when I feel pain	4	8%	6	12%	40	80%
B	Daily living activity						
1.	It annoys me not to practice my hobbies (playing football and riding a bike	19	38%	10	20%	21	42%
2.	I need help when walking	36	72%	11	22%	3	6%
3.	I need help when washing and showering	41	82%	5	10%	4	8%
C	Fatigue						
1.	I feel tired when doing something that doesn't require effort (playing video games.	24	28%	16	32%	10	20%
2.	I feel tired when standing for a short time	9	18%	24	48%	17	43%
3.	I feel tired to spend time with my friends	17	43%	16	32%	17	43%
4.	I feel physically weak	15	30%	10	20%	25	50%
D	Sleep and rest						
1.	I sleep troubled	22	44%	13	26%	15	30%
2.	I'm getting less sleep	25	50%	12	24%	13	26%
3.	My sleep became accompanied by nightmares	17	34%	16	32%	17	34%

Table two showed that most of patients always feel pain or discomfort when do something 44%, most of samples 82% never need help when washing and showering. Half of samples 50% feels physically weak.

Table three: Psychosocial domain

NO.	Item	Never		Sometimes		Always	
A	Positive feeling	F	%	F	%	F	%
1.	My illness is like any other disease that I can cure	17	34%	13	26%	20	40%
2.	I do my part in life like a normal kid	34	68%	9	18%	7	14%
B	negative feeling						
1.	I am worried because of the disease	21	42%	12	24%	17	34%
2.	I feel sad	14	28%	12	24%	24	48%
3.	I feel afraid of the future	30	60%	7	14%	13	26%
C	school achievement						
1.	Difficulty staying in school	17	34%	17	34%	16	32%
2.	I have been absent due to illness and treatment	9	18%	15	30%	26	52%
3.	Difficulty participating in school activities	14	28%	15	30%	21	42%
4.	Difficulty paying attention at school	21	42%	6	12%	23	46%

Table three showed that most of patients feels always their illness is like any other disease that they can cure 40%, most of patients feel sad always 48%. More than half of patients have been absent due to illness and treatment 52%.

Table Four: Chi-square correlation between demographic data and physical and psychological domains.

No.	Demographic data	P-Value	
		Physical domain	Psychological domain
1.	Age	0.136	0.062
2.	Gender	**0.014**	**0.033**
3.	Educational level of child	**0.045**	0.103
4.	Mother Educational Level	**0.011**	**0.005**
5.	Father Educational Level	0.114	0.067
6.	Residence	**0.043**	0.071
7.	Mother Occupation	**0.002**	**0.009**
8.	Father Occupation	**0.010**	0.115

This table showed significant relation between gender and both domains physical and psychological p-value 0.014 and 0.033 respectively. Significant relation between educational level of child and physical domain p-value 0.045. mother education in significant with both domains physical and psychological p-value 0.011 and 0.005 respectively.

*p-value: less than 0.05 = Sig , more than 0.05 Not. Sig

CHAPTER FIVE:-

DISCUSSION

Chapter Five: Discussion

In comparison to healthy children, children with chronic illness are 2.5 times more likely to have psychosocial problems in addition to their physical impairments caused by their illness [35]. Unfortunately, there are few published studies on sickle cell disorders' quality of life. The majority of studies have documented the illness's effect on specific domains. Kumar et al. examined the psychological impact of sickle cell anemia on children's self-concept, anxiety levels, and personal and social adjustment[36]. A multidimensional disease-specific scale was developed to improve the coverage of various health aspects. This scale was used to assess the impact of SCD on various health domains and its impact on the daily lives of these children.

The SCA children were more restricted in their physical activities, such as playing. In these patients, self-care was rarely compromised. Asian/Indian haplotypes are associated with higher Hb F levels and a milder course in India than the three African haplotypes[37]. This results in fewer crises but does not alleviate the physical limitations these children face when they are ill.

The SCA children experienced a greater degree of sadness or disinterest, a lack of support from teachers, school attendance, entertainment and participation in cultural activities, the intensity of weakness and pain, and a realization of being affected by a major illness.

Numerous studies have revealed differences in QOL between affected SCA children and normal children. They have been more domain-specific, with few, if any, addressing the observed differences in SCA. Palermo et al. described a parental assessment of sickle cell disease children. They compared the health-related quality of life scales of 58 sickle cell disease children to 120 healthy children using the Child Health Questionnaire. Additionally, their findings indicated that these children had significantly lower levels of physical, psychological, and social well-being than healthy children. The findings

indicated that sickle cell disease has a significant impact on these adolescents' health-related quality of life[38].

Kater et al. compared the quality of life of sickle cell disease patients and healthy children in Amsterdam. These children performed worse on physical, motor, and daily functioning tests and exhibited a higher level of negative emotions[3]. Fuggle et al. investigated the frequency and severity of sickle-related pain, as well as its impact on quality of life, and concluded that routine pain assessment at home effectively supports children's resilience and improves their quality of life [40]. Using a multidimensional scale would facilitate a more objective evaluation of the effects of various pain management interventions on various domains. Midence K et al. also discussed family and social issues associated with sickle cell disease, concluding that, as with all chronic illnesses, SCA children experience significant psychosocial and practical consequences[41].

In conclusion, the current study confirms previous findings that the majority of children with SCA have limitations in physical activities and psychosocial aspects of their perceptions of their cognitive abilities, health, and future opportunities. This assessment would allow for a more humanistic approach to health care for these patients, not just in terms of symptom relief, but also in terms of ability enhancement. Thus, palliative treatment or interventions can be targeted to improve the most affected domains, and the effect on QOL over the course of the disease can be quantified. The cost-utility method can be used to estimate the advantage of one treatment over another in sickle cell anemia if a quality-of-life scale for that population is available[42]. Additional research in this area will aid in enhancing the reliability of this scale.

CHAPTER SIX:

CONCLUSION AND RECOMMENDATION

Chapter Six: Conclusions and recommendation

6.1 Conclusions:

The current study concluded that:

1. Most of patients were within 6-12 years old.
2. More than half of them were male.
3. Most of family members were six and more.
4. Parents' educational level were primary school for both.
5. More than half of samples were from rural area.
6. Most of patients always feel pain or discomfort when do something
7. Most of samples never need help when washing and showering.
8. Half of samples feels physically weak.
9. Most of patients feels always their illness is like any other disease that they can cure.
10. Most of patients feel sad always.
11. More than half of patients have been absent due to illness and treatment.

6.2 Recommendations:

1. We must focus on this issue because it affects a large group of children in this society, so hospitals and health centers represented by health cadres, especially nurses, must raise the level of awareness of the family on how to deal with their injured children.
2. Organizing training courses for health workers to increase their level of awareness and performance regarding child care.
3. Conducting more research on this issue on a larger number of patients and hospitals, as well as covering new places.

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APPENDICES

Appendix 1:

نوعية حياة الاطفال المصابين بفقر الدم المنجلي

في مدينة البصرة

اولا العوامل الديموغرافية :

عمر المريض:

جنس المريض ☐ ذكر ☐ انثى :

التحصيل الدراسي للطفل

☐ قبل المدرسة:☐ ابتدائي : ☐ متوسط :

☐عدد افراد الاسرة :

التحصيل الدراسي للام :

☐ كلية فما فوق :☐ معهد:☐ ثانوية:☐ ابتدائية:☐ تقرأ وتكتب: ☐امية :

التحصيل الدراسي للاب :

☐ كلية فما فوق:☐ معهد:☐ ثانوية: ☐ ابتدائية: ☐ يقرأ ويكتب :☐اميه:

مكان السكن: ريف: مدينة :

وظيفة الاب:

☐ متقاعد:☐ موظف حكومي:☐ اعمال حرة:☐ كاسب:☐عاطل:

وظيفة الام :

☐ متقاعدة:☐ موظفة حكومية:☐ اعمال حرة: ☐
ربة منزل :

نوعية حياة الاطفال المصابين بفقر الدم المنجلي
quality of life for children with sickle cell anemia

1-المحور الاول: الجانب الجسمي
physical domain

ت	الفقرات	دائما	احيانا	ابدا
1-1	الالم وعدم الراحة pain and discomfort	3	2	**1**
-1-1 1	اشعر بالألم او عدم الراحة عند قيامي بعمل ما			
-1-2 1	اشعر بالـألم بالعظام او المفاصل			
-1-3 1	اشعر بعدم الراحة عند الشعور بالألم			
1-2	النشاطات اليومية Daily living activity	3	2	**1**
-2-1 1	يزعجني عدم ممارسه هواياتي (لعب كرة القدم وركوب الدراجة			
-2-2 1	احتاج الى مساعدة عند المشي			
-2-3 1	احتاج الى مساعدة عند الغسل والاستحمام			
1-3	التعب fatigue	3	2	**1**
-3-1 1	اشعر بالتعب عند القيام بعمل لا يحتاج جهد(لعب العاب الفيديو			
-3-2 1	اشعر بالتعب عند الوقوف لفترة قصيرة			
-3-3 1	اشعر بالتعب لقضاء بعض الوقت مع اصدقائي			
-3-4 1	اشعر باني ضعيف جسديا			
1-4	النوم والراحة Sleep and rest	3	2	**1**
-4-1 1	اصبح نومي مضطربا			
-4-2 1	اصبح نومي قليل			
-4-3 1	اصبح نومي مصاحبا بالكوابيس			

المحور الثانيالجانب النفسي الاجتماعي
Psychosocial domain

ت	الفقرات	دائما	احيانا	ابدا
2-1	الشعور الايجابي	1	2	**3**

			Positive feeling	
			مرضي كباقي الامراض يمكنني الشفاء منه	2-1-1
			اؤدي دوري في الحياة كأي طفل عادي	2-1-2
1	2	3	الشعور السلبي negative feeling	2-2
			اشعر بالقلق بسبب المرض	2-2-1
			اشعر بالحزن	2-2-2
			اشعر بالخوف من المستقبل	2-2-3
1	2	3	انجاز الاعمال المدرسية school achievement	3-2
			صعوبة الاستمرار بالدوام المدرسي	2-3-1
			كثرت غياباتي بسبب المرض والعلاج	2-3-2
			صعوبة المشاركة في الفعاليات المدرسية	2-3-3
			صعوبة الانتباه في المدرسة	2-3-4

Appendix 2 :

الخبراء الذي تم عرض الاستبيان عليهم

ت	الاسم	اللقب العلمي	الشهادة والاختصاص	مكان العمل
1	سجاد سالم عيسى	استاذ	بورد طب اسره	**كلية التمريض جامعة البصرة**
2	سندس باقر داود	استاذ	دكتوراه تمريض نسائية و توليد	**كلية التمريض جامعة البصرة**
3	عبد الكريم سلمان	استاذ مساعد	دكتور تمريض بالغين	**كلية التمريض جامعة البصرة**
4	هشام حسين	استاذ مساعد	دكتور اختصاص اشعه وسونار	**كلية التمريض جامعة البصرة**
5	علي مالك	ماجستير	ماجستير تمريض بالغين	**كلية التمريض جامعة البصرة**

Appendix 3 :

الخلاصة:

معظم المرضى تتراوح أعمارهم بين 6-18 سنة. وكان أكثر من نصفهم من الذكور. كان معظم أفراد الأسرة ستة أو أكثر. كان المستوى التعليمي للوالدين هو المدرسة الابتدائية لكليهما. كانت أكثر من نصف العينات من المناطق الريفية. يشعر معظم المرضى دائمًا بالألم أو عدم الراحة عند القيام بشيء ما. نصف العينات تشعر بضعف جسدي. يشعر معظم المرضى دائمًا أن مرضهم يشبه أي مرض آخر يمكنهم علاجه. يشعر معظم المرضى بالحزن دائمًا. أكثر من نصف المرضى تغيبوا بسبب المرض والعلاج.

التوصيات :

1. يجب التركيز على هذه القضية لأنها تؤثر على فئة كبيرة من الأطفال في هذا المجتمع ، لذلك يجب على المستشفيات والمراكز الصحية المتمثلة في الكوادر الصحية ، وخاصة الممرضات ، رفع مستوى وعي الأسرة بكيفية التعامل مع أطفالهم المصابين. .
2. تنظيم دورات تدريبية للعاملين الصحيين لرفع مستوى وعيهم وأدائهم فيما يتعلق برعاية الطفل.
3. إجراء المزيد من الأبحاث حول هذا الموضوع على عدد أكبر من المرضى والمستشفيات ، بالإضافة إلى تغطية أماكن جديدة.

وفي الختام

لحمد لله الذي قد وفقنا في تقديم بحثنا العلمي لحضراتكم، حيث تحدثنا في موضوع (نوعية الحياة للأطفال المصابين بفقر الدم المنجلي)، وحاولنا بكل جهدنا حتى يظهر البحث بشكله النهائي أمام حضراتكم، ونرجو ألا يكون البحث قد أهدر من وقتكم، بل نأمل أن يكون قد نال هذا البحث العلمي اعجابكم، ولا نقول أن هذا البحث كامل، فإن الكمال من صفة الله عز وجل، بل أننا سوف ننتظر تعليقات الأساتذة الأفاضل وملاحظاتكم، وعلى أن يكون البحث قد نال جزء من الرقي الذي يليق بكم، فإن وفقنا فمن الله الرحمن الكريم، وإن أخفقنا فمنا، ويكفينا شرف المحاولة، وأخيراً نرجو من الله عز وجل أن يوفقنا لما يحبه ويرضاه، وأن يعجبكم هذا النقاش، وصلى الله

على محمد رسول الله صلى الله عليه واله وسلم

تم بعون الله تعالى

جامعة البصرة
كلية التمريض

نوعية الحياة للأطفال المصابين بفقر الدم المنجلي في مركز أمراض الدم في البصرة

مشروع البحث

قدم الى مجلس كلية التمريض في جامعة البصرة في تحقيق جزء من متطلبات الحصول على درجة البكالوريوس في علوم التمريض

من قبل الطلبة

سجاد عبدالكاظم جواد

علي مازن داود

يحيى صلاح حسن

2022_ 2021

بإشراف : الدكتور عادل علي حسين