

Effect of Transitional Educational Health Program of Adolescent Female Students with Sickle Cell Disease.

Khadiga Abd Elgyied G. Hassan⁽¹⁾ Reda Mohamed El-sayed Ramadan⁽¹⁾ Rahma Abd Elgawad M. Elkalashy⁽³⁾ and Abla F.A. Saad⁴

¹ (Lecture of Pediatric Nursing, Faculty of Nursing, Port Said University, Egypt. Assistant Professor of Pediatric Health Nursing, College of Applied Medical Science, Shaqra University, KSA)

² (Assistant Professor of Medical Surgical Nursing, College of Applied Medical Science, Shaqra University, KSA)

³ (Lecturer of Medical Surgical Nursing, Menoufia University, Egypt, Assistant Professor of Medical Surgical Nursing, College of Applied Medical Science, Shaqra University, KSA)

⁴ (Assistant Professor College of Applied Medical Science, Shaqra University, KSA)

Abstract:

Background: Transitional Educational Health Program (TEHP) has a significant positive effect on knowledge of person with chronic disease. It is a cost-effective method to improve the quality of life of person with sickle cell disease (SCD), and is one of the basic steps to control several complications. Spread of SCD in kingdom of Saudi Arabia significantly different in the parts of the country, with the major spread is in the Eastern province, then the Southwestern provinces. The incidence of sickle-cell trait ranged between 2% to 27%, and up to 2.6% will have SCD in some areas.

Aim: The aim of the current study was to develop, implement and evaluate outcomes of transitional educational health program suitable for female adolescent students with sickle cell disease.

A **Quasi-experimental research design** was adopted to conduct this research. This study was carried out in female general secondary schools in Qatif, Eastern Province, Kingdom of Saudi Arabia.

Subjects: A purposeful sample of 82 secondary school aged between 14-18 years, Saudi female adolescent students with sickle cell disease. **Tools:** Two main tools were used: 1) Interview questionnaire sheet, 2) The pre/posttest sheet to evaluate the adolescent knowledge before and after implementation the program developed by the researcher. The sample size was divided into four groups, each group have twenty or twenty-two students. The health program was carried out in two days per week for one week for each group. The pre/post test was applied to evaluate outcomes of transitional health program,

Results: the results showed that approximately 14.6% of study female adolescent students were receiving special educational services, and more than 80% reported SCD interfered with their school achievement. Also, the most (79.3%) of the studied adolescents had no desire to complete SCD treatment. The results showed improvement on the studied adolescents' knowledge about sickle cell anemia.

Conclusion: TEHP for adolescent students with SCD essential for improving their knowledge and their awareness towards disease.

Recommendations: Nurses should include in national educational management program to increase awareness and improve their knowledge towards SCD. Continuous educational and training program concerning management of SCD among health personnel are necessary.

Keywords: Transitional Educational Health Program (TEHP), Sickle Cell Disease (SCD), secondary school student, adolescent.

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I. Introduction

Sickle cell disease (SCD) is the term refers to more than one illness. SCD is a genetic blood disorders affect red blood cell which becomes rigid and unable to carry oxygen effectively to the body. It is characterized by present of abnormal hemoglobin.⁷ The clinical features are varying and may compose of vaso-occlusive, hematological and infectious crises. Then pain and fatal health problem may occur.⁴ Sickle cell disease (SCD) have a lot of types, the commonest type are sickle cell anemia which refers to hemoglobin SS disease and the other type is sickle hemoglobin C disease, also known as hemoglobin SC disease.³

The affected red blood cells in the individual with SCD which composed hemoglobin S are formed like banana in shape, this shape make obstruction on blood vessels, leading to recurrent crisis of severe pain.² Also, the affected cell becomes hard and unable to provide oxygen to the body parts causing ischemia and damage of the multi body organs. The breakdown of the red blood cell easily down causing anemia.¹⁴

Sickle cell trait (SCT) is an inherited state in which both normal hemoglobin and sickle hemoglobin

are produced in the RBCs. SCT is not sort of SCD. Individuals with SCT are generally healthy.⁶ Individuals with sickle cell trait mainly have no health disorders related to SCT, and never affected by sickle cell disease. But they may have child with SCT and may have affected child with SCD.¹²

The severity of clinical features of SCD is differ, between mild and may asymptomatic conditions to severe states need hospitalization. The treatments of the symptoms are found.⁵

The suitable setting to provide ongoing health care of individuals with sickle cell disease is a special center with a professional staff.¹⁸ Which provides health care to individuals with sickle cell disease, not only in the case of crises but also in the free case. First the individuals should be investigated at birth as part of a newborn assessment screening program, in the primary health care center and referred to a special hospital for further investigation if SCD confirmed. An effective communication between the primary health care center and the hospital are essential for appropriate care.¹²

More than 300,000 infant children are born all over the world with SCD mainly from low and middle class, most of them from Africa. Over 70,000 persons in United State of America have sickle cell disease.^{4,26} SCD is present throughout Saudi Arabia; particularly common in the eastern and southern provinces: Qatif (eastern region) 17.0 %, Gizan (southern region), 10.3%, Ula (Northern region) 8.1 % and Mecca (western region) 2.5 % .¹

SCD with a prevalence of 5 % in the world is a common public health carrier with no definite treatment. An effectiveness health program both general and genetic should be done in relation to investigation, management, education (school performance) and marriage.¹⁷

Transitional period from childhood and adulthood is an adolescent period which is a more critical period for life stages, so much attention should be focused in such period. Also, adolescence includes a stage of growth spurt that means more rapid in physical growth, the development of secondary sexual characteristics, and acceleration in cognitive and psychosocial development. As a result, the management of teens with a SCD, issue of self care, in addition of medical and nursing care, to achieve healthy life style.^{13,20}

The Kingdom of Saudi Arabia (KSA) is a developing Kingdom with a large change occur in the lifestyle of the individuals among urbanization, especially over the past 3 decades. Also, the developing of transitional health program for adolescents is very important to improve their healthy lifestyle and encourage them for self care.^{1,19}

Significant of the study

Adolescence is defined as the period of life that begins with the appearance of second sex characteristics and ends with cessation of growth and achievement of emotional maturity. Adolescence surge towards independence which interferes with chronic illness. Chronic illness during adolescence especially SCD runs counter to developmental needs.²⁶ Nurses need to help patients to cope with body image concerns, they must develop an awareness of the teenagers particular fears of forced dependence, rejection by society and loss of face especially with peer group.^{21,23} Many adolescents with chronic illness or developmental disabilities are assisted at home through home health agencies and community agencies work together to meet the physical and psychological needs of the patient. The nurse has an important role in developing transitional educational health program for adolescents²². Therefore, there is an urgent need to developing transitional educational health program for adolescents with SCD.

Aim of the study:

The aim of the current study was to develop, implement and evaluate outcomes of transitional educational health program suitable for female adolescent students with sickle cell disease.

Research hypothesis:

The knowledge of adolescent female students with SCD will improve

II. Methods

Research Design: A Quasi-experimental research design was adopted to conduct this research.

Setting: This study was carried out in female general secondary schools in Qatif, Eastern Province, Kingdom of Saudi Arabia.

Sample size: A purposeful sample of 82 secondary school students aged between 14-18 years, Saudi female adolescent students with sickle cell anemia.

Tool I: Two main tools were used in this study which include, interview questionnaire sheet developed by the researcher.

1-First tool, sickle cell disease assessment questionnaire sheet: It comprised of two parts:

Part I: It included items related to socio-demographic characteristic of the studied adolescent students and their parents, such as age, sex, and adolescent order, and education, occupation of their parents.

Part II: Health status of studied adolescents especially related to sickle cell anemia such as, effect of diseases on lifestyle of adolescents, students' beliefs and attitudes towards sickle cell anemia.

2- Second tool: Patients' level of knowledge

It was developed by the researcher after reviewing the related literature in order to assess patient's level of knowledge before/ after implementation of transitional program in relation to definition of sickle cell disease management, and complications. Reliability test were done whereas Cronbach's Alpha equal 0.70.

Scoring system: Each correct answer had one mark while the incorrect one had zero.

The total score was divided into two categories as follows:

- < 60% was graded as unsatisfactory level of knowledge.
- ≥ 60% was graded as satisfactory level of knowledge.

III. Procedure

- An official permission was granted from administrative personnel of Qatif general female secondary schools to obtain their permission to conduct the study after clarifying the purpose of the study.

-The study tools one and two were developed by the researcher after reviewing the literature relevant to the study and content validity was tested by three experts in pediatric and medical surgical nursing field.

- A reliability was assessed by applying the tools twice by two different data collectors on 10 secondary school female students with SCD using test-retest, who was excluded from the study.

-A pilot study was carried out on secondary school female students with SCD to clarify the validity of the questionnaires and to test the feasibility, clarity and objectivity of the tools. The sample included in the pilot study was excluded from the study sample, and the necessary modifications were done accordingly.

- The stratified sample was divided into four groups, each group have twenty or twenty two students. The transitional educational program was carried out in two days per week for one week for each group. The pre/post test was applied to evaluate outcomes of program.

-The average time needed to complete all tools ranged from 35-45 min for each child.

-A written informed consent was obtained from parents and adolescent who were willing to participate in the research. Before conducting the study confidentiality and anonymity of the adolescent were assured during the coding of the data. Adolescents were assured that the data were not being reused in another research without their acceptance. - The intervention took place between Dhu'l-Hijja to Safar1435 H.

Statistical Analysis

Data were coded and transformed into a specially designed format suitable for computer feeding. All entered data were verified for any errors. Data were analyzed using statistical package for social sciences (SPSS) version 20 windows and were presented in tables. Chi-square analysis was performed. Also mean and standard deviations were computed to evaluate the precipitating factors. An alpha level of 0.05 was used to assess significant differences.

IV. Results

Table (1): The socio- demographic characteristics of studied female adolescent students with sickle cell disease.

		(n = 82)	
		No	%
Age (years):	14- 15	9	11.00
	16 - 18	73	89.00
Mean ± SD		16.44 ± 0.801	
Student order in their family:			
	1 st	10	12.2
	2 nd	20	24.4
	3 rd	50	61.00
	4 th	2	2.4

Living with parents:	80	97.6
Yes	2	2.4
No		
Have a siblings with sickle cell disease?	70	85.4
Yes	12	14.6
No		
School achievement :	12	14.6
Good	70	85.4
Bad		

Table (1) deals with socio-demographic characteristics of the studied adolescents and it can notice that 89% of the studied adolescents, aged between 16- 18 years old. The mean age of them was 16.44±0.801 years. More than two third of them were the 3rd child in their family. In addition, 80% of the studied adolescents were living with their parents. The majority (85.4%) of the studied adolescents had bad school achievement.

Table (2): The socio-demographic characteristics of parents of studied female adolescent students with sickle cell disease.

	(n = 82)	
	No	%
Mothers education:		
Illiterate	2	2.4
Read / write	8	9.8
Primary	10	12.2
Preparatory	10	12.2
Secondary	41	50.0
University	11	13.4
Mothers occupation :		
Hose wife	78	95.1
Working	4	4.9
Fathers education:		
Illiterate	0	0.00
Read / write	10	12.2
Primary	10	12.2
Preparatory	10	12.2
Secondary	41	50.0
University	11	13.4
Fathers occupation :		
Employee	40	48.8
Private business	38	46.4
Retired	4	4.8

Table (2) shows that regard parents' socio-demographic characteristics, a half of both mothers' of the studied adolescents (50%) and fathers of them (50%) had secondary education. Also, 70 % of fathers were employee, while the majority (95%) of mothers of the studied adolescents was house wife.

Table (3): Effect of sickle cell disease on health status of the studied female adolescent students.

		(n = 82)	
		No	%
1-Feel weakness:	Yes	69	84.2
	No	13	15.8
2- Inability to do thing	Yes	66	80.5
	No	16	19.5
3- Bad emotional response:	Yes	67	81.7
	N0	15	18.3
4- Social relation:	Yes	65	79.3
	N0	17	20.7
5- No desire to complete treatment:	Yes	65	79.3
	No	17	20.7

Table (3) shows that according to the effect of sickle cell disease on health status of adolescents students the most (84.2%) of the studied adolescents suffered from weak feeling and 54.12 % of them unable to do thing. 80.5% of studied adolescents had bad emotional response towards disease. Also the most (79.3%) of the studied adolescents had no desire to complete treatment.

Table (4): Comparison between the studied adolescent's knowledge towards sickle cell disease before and after the program.

Knowledge	Before (n=82)		After (n= 82)	
	No	%	No	%
Satisfactory (good)	4	4.9	82	100
Unsatisfactory	78	95.1	0	0.00
Test χ^2 (P-value)	5.060 (0.03*)		6.97 (0.02*)	

*Statistically Significant

Table (4) shows that regarding the knowledge towards sickle cell anemia, before, and after the implementation of the program table (4) illustrated that 95.1% of the studied adolescents had unsatisfactory knowledge before the implementation of the program. While after the implementation of the program the entire (100%) of the studied adolescents had good knowledge about sickle cell anemia. There were statistical significant differences regarding adolescents' knowledge towards sickle cell anemia before and after the implementation of the program.

V. Discussion

Sickle cell disease (SCD) is a group of genetic defects distinguished by defecting in hemoglobin molecules, failing of blood flow, reducing oxygen amplitude of red blood cells, hurting of organ, and occurring of complications.¹⁷ Sickle cell disease effects millions of people worldwide. As a result, treatment for sickle cell anemia is usually aimed at avoiding crises, relieving symptoms and preventing complications.²⁶

Adolescence has been recognized as the first obstacle to health promotion for the reason that a lot of numerous healthy practices are acquired in teen. Father and mother have the essential accountability to reassure this stage of growth and development but many characteristics of adolescents make them susceptible to included in health unfavorable behaviors.²⁴ Teens who have sickle cell anemia must manage their condition, while also dealing with the stresses of the teen years. These teens also face some specific stresses related to sickle cell anemia. Including body-image problems, coping with pain and fear of addiction from using strong pain medicines and living with uncertainty.¹⁰

The schools play a worthy role in the students' life. It is generally the key setting for promoting students' health and wellbeing.¹¹ The school has the opportunity to provide the base for many standard program and high coverage of adolescent. The intervention to improve healthy, has been used in the programs implemented in school.²⁵

Self-performance, social assistance, socio-economic state, and self-care have been recognized as serious concepts correlated with the management of SCD and all chronic disorder. Regarding to the scientific research self-care affects positively in the prognosis of disease and the disease complications affect in it.¹³

Adolescents and children with SCD and their parents scored significantly lower on several health related quality of life domains including; general physical, motor and independent daily functioning.⁸

In Saudi culture, several factors may explain the process of psychological coping among adolescents with SCD. First, the extended family pattern in Saudi Arabia; family provide individuals suffering from anxiety the presence of “safe persons” around them and hide active symptoms of anxiety, maintaining them functional in a compensatory behavior.⁹

In the present study, the studied adolescents with SCD aged between 14 to 18 years with a mean of 16.9 ± 17 years. From the point of view of the researcher these may due to characteristics of the study sample.

Studied adolescents with SCD, have a medium socio-demographic profile in terms of parental educational status and family income. From the point of view of the researcher these may due to the most of fathers of the studied adolescents were employees, which mean they had only salary.

As regards, socio-demographic characteristics of parents of the studied adolescents, a half of both mothers' of the studied adolescents and fathers of them had secondary education. Also, less than a half of

mothers were house wife. The majority of studied adolescents had bad school achievement. This results corresponding with ¹⁵ who found that absenteeism may be the largest obstacle to school success for some children with sickle cell disease. Also, ⁸ stated that children and adolescents may be absent a lot due to clinic visits, pain crises or other health problems which leads to bad school achievement⁴. Suggested that children and adolescents should encourage participating in extracurricular activity in which they should excel.

According to the effect of sickle cell disease on health status of the studied adolescents, the most of the studied adolescents suffered from weak feeling, and had bad emotional response towards disease, unable to do thing. From the point of view of the researcher these may due to effect of disease. These results go in one way with ⁶ who found that adolescents and young children with SCD complained from sad feeling and easily fatigue.

In addition more than a half of the studied adolescents had no desire to complete treatment. From the point of view of the researcher these may due to a half of studied adolescents suffered from bad emotional response towards disease. This results corresponding with ²² who found that the most of adolescents with sickle cell anemia had no desire to complete treatment.

Regarding the knowledge towards sickle cell disease, before, and after the implementation of the program the majority of the studied adolescent female students had unsatisfactory knowledge before the implementation of the program. While the knowledge of all studied adolescents about sickle cell disease had improved after the implementation of the program. From the point of view of the researcher, it could be reasonable relate the results that the program was beneficial to the secondary school adolescents with SCD. This result goes on one way with ²⁴ who indicated that the knowledge of adolescents was not satisfied in pretest, and it became good in the post-test.

VI. Conclusion

Study findings supplement preceding studies and participate to improve knowledge of adolescent with SCD. To facilitate nurse–patient communication, point to areas where patients may experience serious problems during this transitory phase, can be used as diagnostic tools for follow–up care.

VII. Recommendation

Based on the findings of the current study the following was recommended:

- A well organized and structured transitional educational health program of sickle cell patients should be established for patients and their family.
- Health care provides should take time to explain in depth the managements of sickle cell diseases for patients and their family.
- The mass media need to play an important role in health education for sickle cell anemic patients.

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