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Assessment of Hemophilic Teenagers Life Style in Al Basrah City

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Abstract

Objective(s): to assess of hemophilic teenagers life style and its treatment upon the life style of hemophilic teenagers and find out the relationship between hemophilic teenagers life style & their demographic characteristic. A descriptive study was conducted in the blood diseases center in Al Basrah from15of October 2018 to 12 of March 2019. Non-probability [purposive] sample of [32] patients age [10-22] years with hemophilia hospitalized for management were selected. Data were analyzed by using frequencies, percentages, mean of score, Pearson correlation, and multi-regression analysis. The data was collected through questionnaire and semi-structured interviews. The data were described statistically and analyzed through use of the descriptive and inferential statistical analysis procedures. The results of the study indicated that the one third of the sample were[16-20] years represent[56.3%]of the total sample and [75%]of the sample were graduated from primary school,[93.7%]of the sample have 1-2   affected brothers,[56.6%] of the sample were unemployed, and [71.9%]of hemophilic teenagers were from family of moderate level of socioeconomic states[SES]. Over half [56.3%]of the hemophilic adolescents suffer from the knee joint which is the most affected part by bleeding ,[68.75%]suffer from bruises, and[53.1%] have a family history of hemophilia.

Key wards: *Assessment, Life Style, Teenagers, Hemophilia.*

Introduction

The impact of chronic illness is a major burden on both the individual patient and society, it may affect the quality of life and impair schooling and work. Hemophilia is one of the chronic diseases which interferes with the individuals usual activities and has an impact on his physiological, psychological and social functioning. It's an inherited interference with blood coagulation [1]. There are numerous hemophilia types, each involving deficiency of a different blood coagulation factors; classic hemophilia "type A" is caused by the lack of factor eight (VIII), it is the most common and usually most severe type of hemophilia, Christmas disease "type B" and "type C" hemophilia are cause by the lack of factor **IX** and **XI** respectively. Mentioned that adolescents is a period of transition from childhood to adulthood and important dramatic changes in psychological and physical as a chronic illness significantly interfere with these demands [2]. Adolescents have emotional coping problems such as: anxiety, fear, depression, loneliness, low self-esteem, they are worried about their future life choices and the stress that is associated with the diagnosis and treatment of long term illnesses and late complications powerfully interfere with their activities of daily life [3]. Lifestyle is expressed in both work and leisure behavior patterns and (on an individual basis) in activities, attitudes, interests, opinions, values, and allocation of income. It also reflects people's self-image or self-concept; the way they see themselves and believe they are seen by the others. Lifestyle is a composite of motivations, needs, and wants and is influenced by factors such as culture, family, reference groups, and social class. The

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analysis of consumer life styles (called psychographics) is an important factor in determining how consumers make their purchase decisions [4].

Methodology

Study Design: A descriptive study design was conducted on adolescents having hemophilia age range between 12 years up to 22 years. Data collection started from December 10th, 2018 through January 10th, 2019 in order to assess hemophilic teenagers' lifestyle.

Study Sample: A purposive "non–probability" sample of (32) patients age (12-22) years with diagnosed hemophilia for management were selected from the patients who visit the center.

The Study Instruments: Data were obtained by the investigators who interviewed hemophilia teenagers and filled out the questionnaire which is designed for the purposes of this study and consisted of three parts and a covering sheet that includes statement to introduce the investigator and purpose of the study. Each hemophilic adolescent took approximately (20-30 minutes) to respond to the questionnaire and answer them.

The questionnaire format consists of two parts:

Part I: Sample Demographic Characteristic:

This part includes two sections:

Section I: Hemophilic Teenagers' Demographic Data: It included demographic data concerning the respondents' general characteristic of age, educational level, total number of sisters and brothers, number of carrier sisters and occupational status.

Section II: Disease Related Information: It includes items concerning hemophilia disease itself such as, bleeding parts at the first time of diagnosis, age at on set, which joint more exposed to bleeding, severity of the disease depending on factors rate taken from the patient's report in the hemophilic center of hereditary disease.

Part II: Assessment of Hemophilic Teenagers' Lifestyle Questionnaire: This questionnaire is comprised of structured (125 items) concerning 7 domains.

These domains and their sub-domains are:

1•Physical domain (23 items) it is composed(3) sub-domains which includes: pain, sleep and relaxation, mobility and transportation, all of these items explained how the disease affects the physical characteristic of hemophilic adolescents.

2•Dietary Habits (10 items) related to meals that content of protein, fat, carbohydrate, vitamins and mineral, such as milk, meat, fish, fruit, vegetable which help in the growth.

3•Independent domain (17 items) it is composed of (3) sub domains which includes: work (employability), school achievement, functional and daily activities.

4•Psychological domain (30 items) comprised of (5) sub domains related to positive feeling, negative feeling which includes: mood, feel of pleasure, fear and anxiety, hopeless and depression, harmony with others.

5•Social domain (20 items) which includes relationship with others, such as: parents, brothers, sisters, or friend.

6•Recreational and Sportage activities (17 items)

7•Religious domain (8 items) it consists of (2) sub-domains: positive and negative beliefs.

The lifestyle scale (125 items) were rated according to a 3-pointslikert scale as (agree, I don't know, disagree) and the rate of scores as 3 for agree and 2 for I don't know and 1 for disagree. The total scores ranged from (125-375) the lowest score explains no effects on Lifestyle.

Data collection: the investigators collected data by questionnaire and semi-structured interview technique used with hemophilic teenager, after taking the initial consent of each adolescent to participate in the study. The process started from 10th of December 2018 until the 10th of January 2019. An approximately (20-30) minutes spends with each hemophilic adolescent to complete the interview and filling of the questionnaire format.

Rating and Scoring of the Questionnaire Format

The items have been rated and scored according to the following patterns: Three point Likert scales is used for rating the items as always =3, sometimes =2, never =1, for all items. Except the sub-domains of positive feeling and social support which rated reverse for always =1, sometimes =2, never=3. The lowest score explains no effects on QoL domain while the highest

score reflects the effects of ALL upon QoL domain of teenagers.

Data Analyses: The data of the present study were analyzed by using the Statistical Package for the Social Sciences (SPSS) for windows, version 20. The descriptive statistical measures of frequency, percent, Mean, Standard Deviation and the Weighted Mean were applied. Linear regression was applied as an inferential statistical measure.

The mean of score calculated according to the following equation:

$$\text{Mean} \quad \text{of} \quad \text{Score:}$$
$$M = \frac{f_1 \times S_1}{n} + \frac{f_2 \times S_2}{n} + \frac{f_3 \times S_3}{n}, \quad f =$$

Frequency, S = score, n = Sample size

A mean of score of 1.5 was considered low; (1.5-2.5) was considered moderate and 2.5 was considered high.

Multiple Linear Regression: Polite and Hungler [5] mentioned that multiple regression the correlation between two variable dependent variable (x) and independent variable (y) more than one variable.

Results And Discusion

The participants' mean age (SD) is (17.8 ± 4.9), more than the half of them are within the age group 16-20 years-old age (n= 18; 56.3%), the majority of them still enroll in schools (n = 24; 75.0%), more than two fifth of them are preparatory school students (n = 13; 40.6%), the most reasons of leaving school as they reported is illness (n = 7; 21.9%), more than one third of them have 3-4 brothers (n = 14; 34.8%), a half of them have 1-2 sisters (n = 16; 50.0%), the vast majority of them reported that they have 1-2 brothers and sisters (n = 30; 93.7%), the mostly ill person relative to the father is "the uncle" (n = 6; 46.2%), the mostly ill person relative to the mother is "the uncle" (n = 7; 43.8%), the occupation of most of them is "not working student" (n = 21; 65.6%), the occupation of more than the third of participants' fathers is employed (n = 12; 37.5%), the occupation of most of participants' mothers is housewife (n = 21; 65.6%), more than one fifth of participants' fathers is intermediate school graduate (n = 7; 21.9%), more than one third of participants' mothers is primary school graduate (n = 12; 37.5%), the majority of families is nuclear (n = 27; 84.4%), less than the half of participants' families have 4-6 persons (n = 15; 46.9%), the number of home rooms for the majority of participants is 2-4 rooms (n = 23; 71.9%), the majority of participants' families have their own homes (n = 22; 68.8%), and more than one third of participants reported that the onset age is < one year (n = 12; 37.5%).

Table (1): Participants Medical History

	Variables	Items	Yes		No	
			Freq.	%	Freq.	%
1.	The most affected joint	Elbow	15	46.9	17	53.1
		Ankle	12	37.5	20	62.5
		Knee	18	56.3	14	43.8
2.	Site of bleeding	Postpartum hemorrhage (via umbilici)	6	18.8	26	81.3
		Circumcision	0	0.0	32	100.0
		Bleeding through the mouth	6	18.8	26	81.3
		Bleeding on trauma	22	68.75	10	31.25
		Impact with something	21	65.6	11	34.4

***Cont...* Table (1): Participants Medical History**

3.	Causes of bleeding	Unhealthy diet	4	12.5	28	87.5
		Accidents in home, school and work	21	65.6	11	34.4
		Rigorous exercise	14	43.8	18	56.3
		Violence in the street, home and School	11	34.4	21	65.6
		Difficulty in accessing health care Services	7	21.9	25	78.1
		Loss of family member	2	6.3	30	93.8
4.	Severity of Illness	Items	Frequency		%	
		Mild	5		15.6	
		Moderate	17		53.1	
		Severe	10		31.3	

No. : Number, F : frequency , % : percentage *Yes= 7 second degree+4 third degree

Table (1) demonstrates that the most affected joint is the knee (n = 18; 56.3%), the mostly reported site of bleeding is bleeding on trauma (n = 22; 68.75%), more than the half of participants reported that that their illness is moderate in severity (n = 17; 53.1%), and most of participants reported that most of the causes of bleeding is accident in home, school and work (n = 21; 65.6%).

Table (2): Mean, Standard Deviation, Weighted Mean and Relative Sufficiency of Participants' Physical Aspect

List	Items	M (SD)	Weighted Mean	Relative Sufficiency
	Pain			
1.	The pain that I experience is permanent	2.2 ± 0.9	11.8	0.70
2.	The pain that I experience is not severe	2.0 ± 0.9	10.8	0.83
3.	I experience joint stiffness	2.0 ± 1.0	10.5	0.70
	Sleeping and Relaxation			
4.	I've nightmares	2.1 ± 1.0	11.5	0.68
	Mobility and Transportation			
5.	I feel embarrassed because of my slow steps	2.2 ± 0.9	11.8	0.70

Table (2) reveals that the most affecting item among the sub-domain of pain is "The pain that I experience is not severe" (relative sufficiency = 0.83), the most affecting item among the sub-domain of sleeping and relaxation is "I've nightmares" (relative sufficiency = 0.68), the most affecting item among the sub-domain of mobility and transportation is "I feel embarrassed because of my slow steps" (relative sufficiency = 0.70).

Throughout the course of the present study, and as it has been shown in table (1) , that the majority of study participants are within the age group 16-20 years-old age (n= 18; 56.3%)the majority of them still enroll in schools (n = 24; 75.0%), more than two fifth of them are preparatory school students (n = 13; 40.6%), and the most reason of leaving school is illness (n = 7; 21.9%), the vast majority of them have 1-2 brothers and sisters (n = 30; 93.7%), the mostly ill person relative to the father is "the uncle" (n = 6; 46.2%),while the mostly ill person relative to the mother is "the uncle" (n = 7; 43.8%), the majority of study participants are "not working (n = 21;

65.6%). Regarding the occupation of parent, more than the third of participants' fathers is employed (n = 12; 37.5%), and the occupation of most of their mothers is housewife (n = 21; 65.6%). In respect to parent's education, more than one fifth of participants' fathers is intermediate school graduate (n = 7; 21.9%), while more than one third of participants' mothers is primary school graduate (n = 12; 37.5%). Moreover, relating to the type of family, the majority of families is nuclear (n = 27; 84.4%), less than the half of participants' families have 4-6 persons (n = 15; 46.9%), the number of home rooms for the majority of rooms (n = 23; 71.9%), the majority of participants' families have their own homes (n = 22; 68.8%). Compliance with treatment is also a major to concern to prevent the long term complications of the disease. In this age group hemophilic adolescents are more exposed to injuries which lead to visiting the hemophilia center for treatment [7]. The highest percentage of hemophilic adolescents (75%) graduated from primary school, more than half of them are suffering from more than usual absence from school and this may interrupt the educational process and limit their activities [8]. Hemophiliac adolescents miss significantly more school days than their healthy counterparts this indicated that hemophilia disease had a significant impact on the lives of the teenagers' students in the community. In respect to adolescent siblings the majority of teenagers have 1-2 brothers and also 1-2 sisters [9]. The result shows that the majority of participant experience with not severe pain (relative sufficiency = 0.83), while other finding indicate that the majority of their sample(74.2%)feel pain especially when doing anything during the period of bleeding in the joints that restricted their movement, they suffer from repeated hemorrhage and this represent(75.8%)of the sample [10]. Regarding pain, bleeding episode, disease severity in hemophilia patients are important consequences and lead to impairment of life style in hemophilia adolescents [11]. Regarding sleeping, the majority of participants have nightmares" (relative sufficiency = 0.68),this finding is supported by Manocchia et al who reported that there is a direct association between sleep problem and decrements in health related quality of life ,sleep problem may be a significant confounding factor in the interpretation of health outcome among patients with chronic disease .regarding mobility and transportation , the majority of participants embarrassed because of their slow steps" (relative sufficiency = 0.70). these results indicated that the patient with hemophilia may have a problem with quality of life rather than other patients who should be encouraged to live a normal life and they only need to be aware of the potential danger of trauma [12]. Examine the validity and reliability of the Dutch Arthritis Impact Scale of Individual with severe hemophilia on the life style domains, he found that the physical health component and life style were significantly correlated(pearson's 0.53), these data support the validity and reliability of the physical aspects of the patients with severe hemophilia [13].

Conclusion

The finding of the study have approved that there is a highly significant association between the hemophilia and its treatment and the educational level, affected brothers, bleeding part, disease severity as well as, a significant association with SES.

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Conflict of Interest: None to declare.

Ethical Clearance: All experimental protocols were approved under the College of Nursing, University of Basrah, Iraq and all experiments were carried out in accordance with approved guidelines.

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