

ANXIETY AND DEPRESSION AMONG CHILDREN WITH HEMOPHILIA AT ABOU EL-RISH HOSPITAL

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ABSTRACT

Background: Children with hemophilia encompass extreme stress, deprivation and serious limitations associated with their disease. Hemophilia will have a huge negative impact on the psychological, social and economic health of the affected children and their families. **Aim:** the study aimed to assess anxiety and depression among children with hemophilia. **Design:** A descriptive exploratory design was utilized for the current study. **Sample:** A sample of convenience of 100 hemophilic child from Hematology Center at Abou El-Resh University Hospital. **Data collection tools:** Socio-demographic and Medical Data Sheet, Center for Epidemiological Studies Depression Scale for Children (CES-DC), and Screen for Child Anxiety Related Disorders (SCARED). **Main findings:**

Findings of the current study revealed that, 86% of the sample suffering from anxiety disorders and (98%, 97%, 94%, 89%, and 62%) of them suffering from, significant somatic symptoms, generalized somatic anxiety disorders, separation anxiety disorders, social anxiety disorders, and school significant avoidance respectively, also, the results revealed that, most of the studied child (94%) suffering from depression. **Conclusion:** The study concluded that, anxiety disorders and depression is common among children with hemophilia. **Recommendations:** Psychological interventions for hemophilic children accompanying pharmacological intervention is essential.

Key Words: *anxiety, depression hemophilia, children*

INTRODUCTION

Hemophilia A and B are genetic X-linked disorders due to deficiency (or absence) of coagulation factor VIII or IX, respectively. Bleeding risk is related to the severity of factor deficiency. Frequent joint bleeding (haemarthrosis) can lead to a severe hemophilic arthropathy resulting in disabilities. Nowadays, the availability of recombinant factor VIII and factor IX concentrates has changed the care of children with hemophilia [1].

Hemophilia is a group of genetic diseases characterized by reduced to obviously altered blood clotting resulting from a deficiency of one of the factors essential for blood coagulation, Hemophilia is an X-linked congenital bleeding disorder which occurs at a frequency of approximately 1 in every 10,000 births; hemophilia divided into two types: hemophilia A, and hemophilia B, hemophilia A caused by a deficiency in coagulation factor VIII, representing 80-85 % of the total number of diagnosed cases of hemophilia, hemophilia B is caused by deficiency in coagulation factor IX, and represent 15%-20% of the total diagnosed cases of hemophilia, both of which are related to a mutation of the clotting factor gene. The number of affected persons worldwide is estimated to be about 400,000 [2].

One of the main important issues of parents and health care givers for hemophilic children are the psychological and behavioral problems which may affects their quality of lives. As the

hemophilic in deals with chronic arthropathy, fatigue, and limb complication [3]. Hemophilia can lead to emotional, behavioral, and cognitive problems [4].

Hemophilic children experience sever stress, and marked limitations related to their disease [5]. Perceived stress can interfere with brain functions and may result in emotional and behavioral dysfunction. Hanson and colleagues indicated that difficult life circumstances in childhood can decrease hippocampus and amygdala volume which cause behavioral disorders [6]. Children with hemophilia are often deprived of regular life activities because of the fear of recurring episodes of bleeding [5].

Hemophilia have a serious negative impact on the psychological, social and economic health of the affected children and their care givers Children with hemophilia are reported to have a high burden of emotional difficulties and have been reported with conditions like lower self-perception and depression. Studies have reported that children with hemophilia are less joyful, less open and caring [7].

Fatigue, weakness and discomfort as a cause of prolonged bleeding with hemophilic children. The vitality of children will be reduced and it will provide a context for developing a sense of anger and frustration [8]. Parents of children with hemophilia show overprotective behavior towards their children, resulting in anxiety and chronic depression in the children [9]. Children with hemophilia would be more absent from the school due to occasional bleeding episodes. On the other hand, physical limitations prevent them from participating in school activities and do their homework same as their healthy peers. This could explain their poor academic achievement [10].

Patients with hemophilia experience different types of mood disorders includes depression as a cause of pain and disability [11]. A higher proportion of elderly hemophiliacs with depression was reported compared to the aged-matched general population in Italy including a correlation between depression. Despite much improvement in treatment, children with hemophilia still face many important clinical challenges, such as demanding treatment regimens, severe acute pain related to haemarthrosis, debilitating hemophilic arthropathy or inhibitor development [12]. which are associated with increased emotional distress [13].

SIGNIFICANCE OF THE STUDY

Hemophilia A is more common than hemophilia B, representing 80–85% of the total hemophilic population. According to the WFH Global Survey, there were an estimated 5,050 people with hemophilia according to World Federation of Hemophilia (PWH) in Egypt in 2013 [14].

Results of this study will increase nurse's knowledge related to depression and anxiety among children with hemophilia; this might be incorporated in the future plan of care for such group of patients. In addition, such data may have an impact on the provided care in the way to be cost effective and to decrease the load upon personal and hospital resources. It might also generate an attention and motivation for further researches into this area.

SUBJECTS AND METHODS

Aim of the Study

The aim of this study was to assess anxiety and depression among children with hemophilia.

Research Question

1. What are the common anxiety disorders among children with hemophilia?
2. What is the level of depression among children with hemophilia?
3. Is there significant relation between anxiety and depression in relation to socio-demographic characteristics of among children with hemophilia?

Research Design

A descriptive exploratory design was utilized for the current study; such design fits the nature of the problem under investigation. Descriptive exploratory research design, as the name states, intends merely to explore the research questions, it conducted in order to determine the nature of the problem, this type of research is helps to have a better understanding of the problem. When conducting exploratory research, the researcher ought to be willing to change his/her direction as a result of revelation of new data and new insights (Saunders, Lewis, & Thornhill, 2012) [15].

Sample

A sample of convenience of 100 hemophilic child diagnosed as hemophilia A- or B based on factor VIII, or IX activity level of 30% or less, who attended at Hematology Center, New Children Hospital, Cairo University. Inclusion criteria were: male, aged from 6 to less than 18 years, diagnosed with hemophilia, factor level <1% of normal, children with other chronic diseases, mental retardation, mild and moderate hemophilia were excluded from the study.

Setting

The study was carried at Hematology Center at Abou El-Resh Hospital, University Hospital. The number of registered cases diagnosed with hemophilia (199) and 108 of them were regularly follow up monthly. The center provides diagnosis of new cases, regular follow up, prevention and screening, genetic counselling, prompt management of bleeding, management of complications, and attention to psychosocial health.

Tools of Data Collection

Data were collected over a period from July 2016 till October 2017 by using Socio-demographic and medical Data Sheet, Center for Epidemiological Studies Depression Scale for Children (CES-DC); and Screen for Child Anxiety Related Disorders (SCARED).

1. Socio-demographic and Medical Data Sheet.

It was designed by the investigators and it includes personal data, such as; child's age, gender, education status, father and mother education, father and mother occupation etc. Medical information includes presence of other diseases, school achievement, and schedule of follow up.

2. Center for Epidemiological Studies Depression Scale for Children (CES-DC) Weissman, et al. (1980) [16].

It is a 20-items self-report depression inventory with possible scores ranging from 0 to 60. The scale assesses the depression state among children during the week before the assessment for example "I was bothered by things that usually don't bother me", "I felt like I was just as good as other kids". Each response to an item is scored as follows: 0 = "Not at All"; 1 = "A Little"; 2 = "Some"; 3 = "A Lot". However, items 4, 8, 12, and 16 are phrased positively, and thus are scored in the opposite order: 3 = "Not at All"; 2 = "A Little"; 1 = "Some"; 0 = "A Lot". Higher CES-DC scores indicate increasing levels of depression. The developers of the CES-DC, have used the cutoff score of 15 as being suggestive of depressive symptoms in children and adolescents. Test-retest reliability was tested by using Cronbach's alpha and it was 0.77.

3. Screen for Child Anxiety Related Disorders (SCARED): Birmaher, et. al. (1997) [17].

It was designed specifically to measure anxiety disorders among children. The SCARED consists of 41 three point- Likert scale items. For scoring; score 0 = Not true or hardly ever true, 1= somewhat true or sometimes true, and 2= very true or often true. Total score of ≥ 25 may indicate the presence of an Anxiety Disorder. Scores higher than 30 are more specific. A score of 7 for items 1, 6, 9, 12, 15, 18, 19, 22, 24, 27, 30, 34, 38 may indicate Panic Disorder or Significant Somatic Symptoms. A score of 9 for items 5, 7, 14, 21, 23, 28, 33, 35, 37 may indicate Generalized Anxiety Disorder. A score of 5 for items 4, 8, 13, 16, 20, 25, 29, 31 may indicate Separation Anxiety Disorder. A score of 8 for items 3, 10, 26, 32, 39, 40, 41 may indicate Social Anxiety Disorder. The scale was translated by the investigator in Arabic and tested for reliability by using test-retest reliability coefficient, was 0.84 with a two-week interval.

Procedure

An official permission was granted for the director of Hematology Center at New Children Hospital, Cairo University. After explaining the aim of the research, the investigators met with potential subjects and /or their relatives, explained the purpose of the study, assured them about confidentiality and anonymity, and finally invited them for participation. They were also informed about their right to accept or refuse to participate in the study. Assessment was carried out by using the selected tools. Each participant and/or the relative were interviewed individually, in a semi-structured interview, for about 30 to 45 minutes. The questionnaires were read, explained, and the choices were recorded by the investigators. The subjects were asked about their socio-demographic status which includes age, education, place of residence, etc.

Also, data related to depression, and anxiety was collected by the investigators; the data collection took place in the period from March 2018 to April 2019.

Pilot study

A total of 10% of the sample were recruited for the pilot study to examine clarity, and feasibility of the study. All subjects included in the pilot study met the criteria for inclusion, no further modification was done for all utilized tools.

Ethical Considerations

All children and their caregivers were informed orally that the information will be used only for research purpose and anonymity and confidentiality of each was protected by the allocation of a code number for each response to the questionnaire. Children and their caregivers were informed that, they can withdraw at any time during the study without giving reasons. Their withdrawal will not affect the care they are receiving and relationship with the investigators.

PRESENTATION AND DATA ANALYSIS

It is clear from table (1) that, the studied sample consisted of 100 hemophilic male children, the mean age of the studied children was 8.63 ± 2.78 . As for educational level (20%, 17%, 15%, 12%, 11%) were in second year, third, first, fifth, and sixth year of primary school respectively. Also, table 1 revealed that the children educational achievement was (48%, 22%, 20%) was good, pass, and fail respectively, and only 3% of them were excellence achievement in education.

Table 1: Frequency distribution of studied sample according to Sociodemographic characteristics (n=100)

Items	No	%
1-Age (years)		
- 6-	61	
- 10-	35	
- 15 to less than 18 years	4	
M±SD 8.63±2.78		
2-Educational level		
- Primary school	84	84
- Preparatory school	16	16
3-Educational achievement		
- Excellent	3	3
- Very good	7	7
- Good	48	48
- Pass	22	22
- Fail	20	20

Table 2 shows that, the mean length of illness 48.9 ± 39.9 month, also two quarter (66%) of them follow up monthly in outpatient clinic. Figure 1 revealed that more than half of them (65%, 18%, 11%, and 6%) come to follow up with their mothers, father, with parents, and their relatives. Moreover, figure 2, and 3 revealed that (43%, and 48%) of the studied sample their mother and father middles educational level respectively.

Table 2: Frequency distribution of studied sample according to clinical characteristics (n=100)

Items	No	%
1- length of illness (years)		
- Less than 24 months	36	36
- 25- 48 month	27	27
- More than 48 months	37	37
M±SD 48.9±39.9		
2- Follow up rate		
- Monthly	66	66
- Twice month	9	9
- weekly	25	25

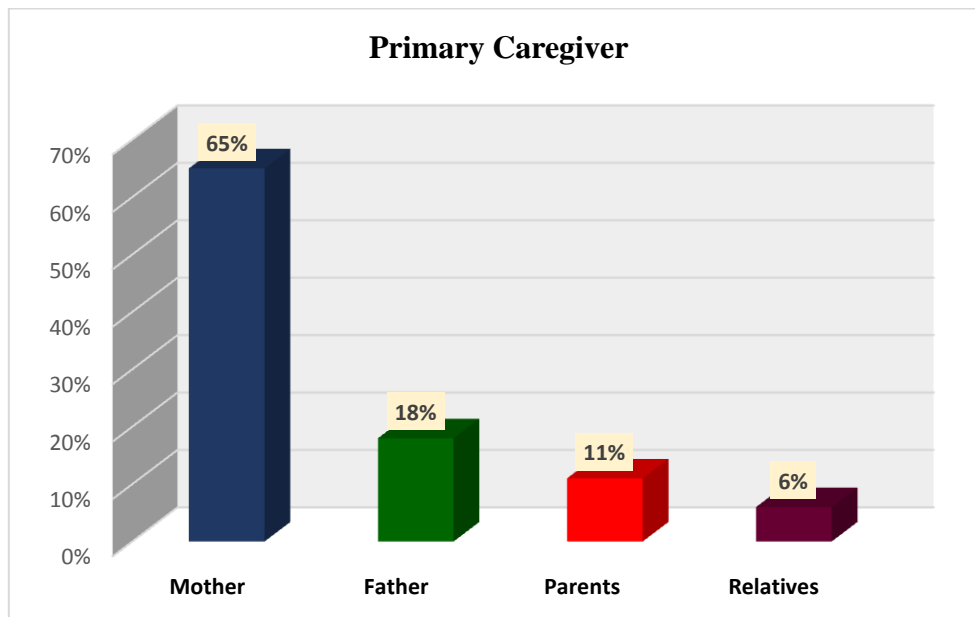


Figure 1: Frequency distribution of the studied patients according to primary caregiver

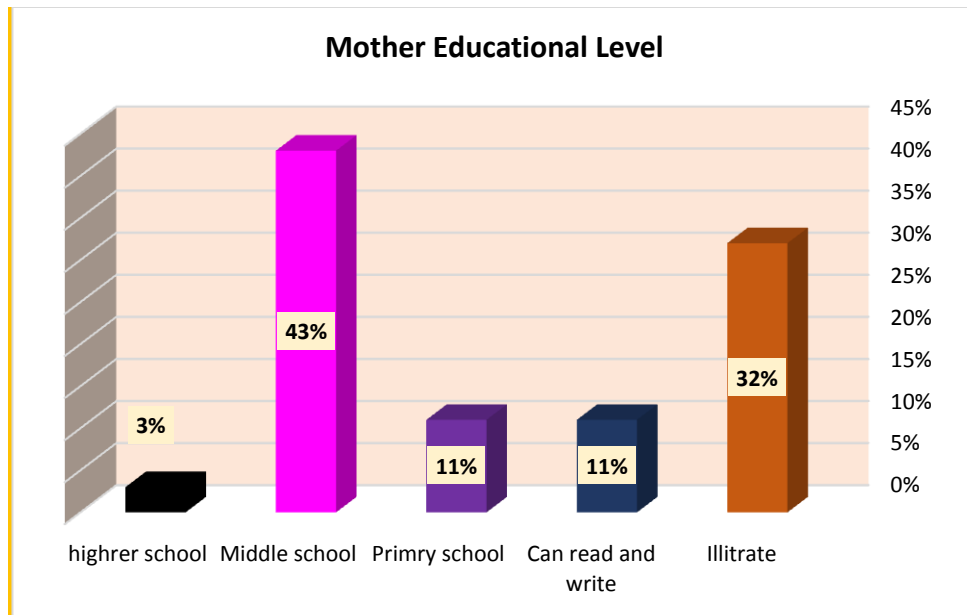


Figure 2: Frequency distribution of the studied patients according to mother educational level

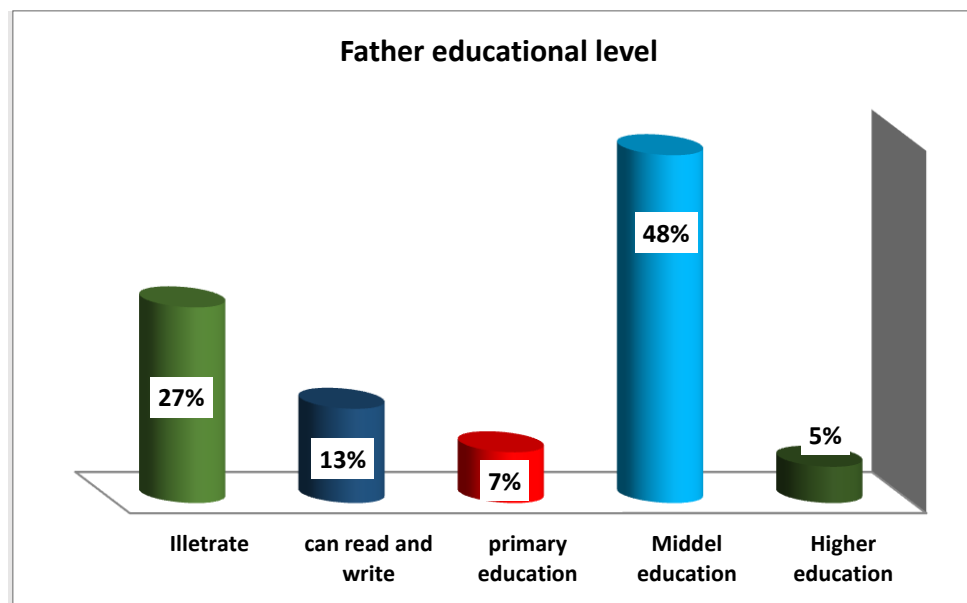


Figure 3: Frequency distribution of the studied patients according to mother educational level

As observed from figure 4 and 5 that 81% of the studied sample their father were working and 89% of them their mother were housewife. Also, figure 6 showed that, 84% of the studied sample diagnosed as hemophilia A, and 14% diagnosed as hemophilia B.

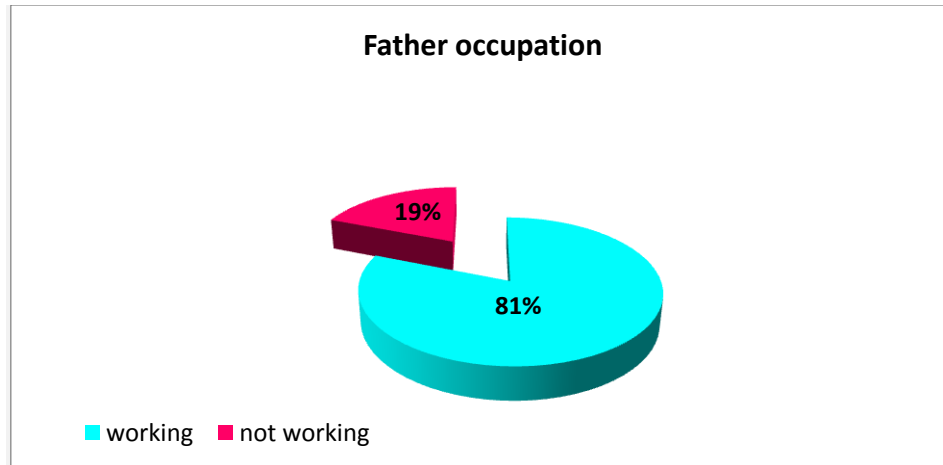


Figure 4: Frequency distribution of the studied patients according to father occupation

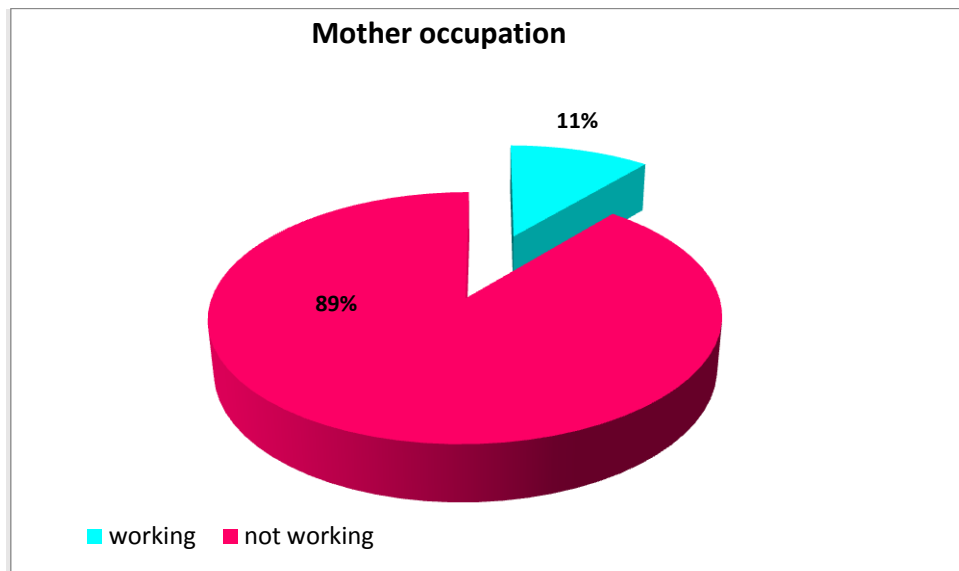


Figure 5: Frequency distribution of the studied patients according to mother occupation

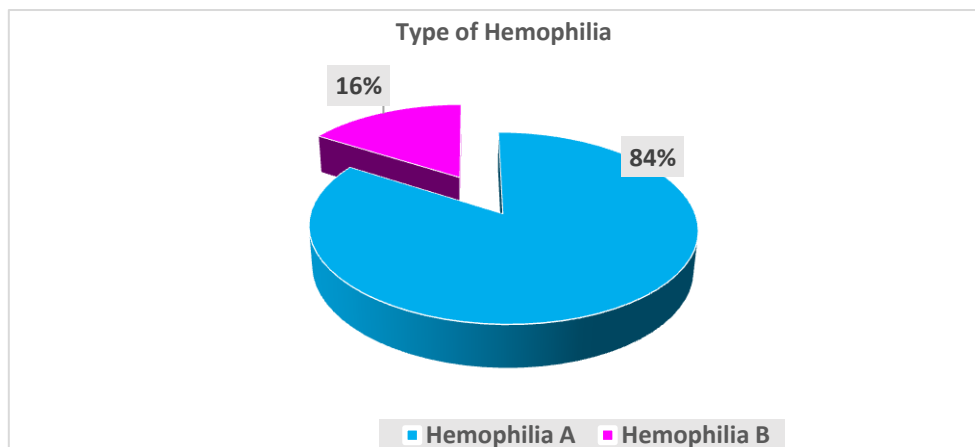


Figure 6: Frequency distribution of the studied patients according to type of hemophilia

As regards frequency distribution of anxiety disorders among the studied sample figure 7 showed that, 86% of the studied sample suffering from anxiety disorders. Moreover figure 8 revealed that, (94%) of the studied sample suffering from depression.

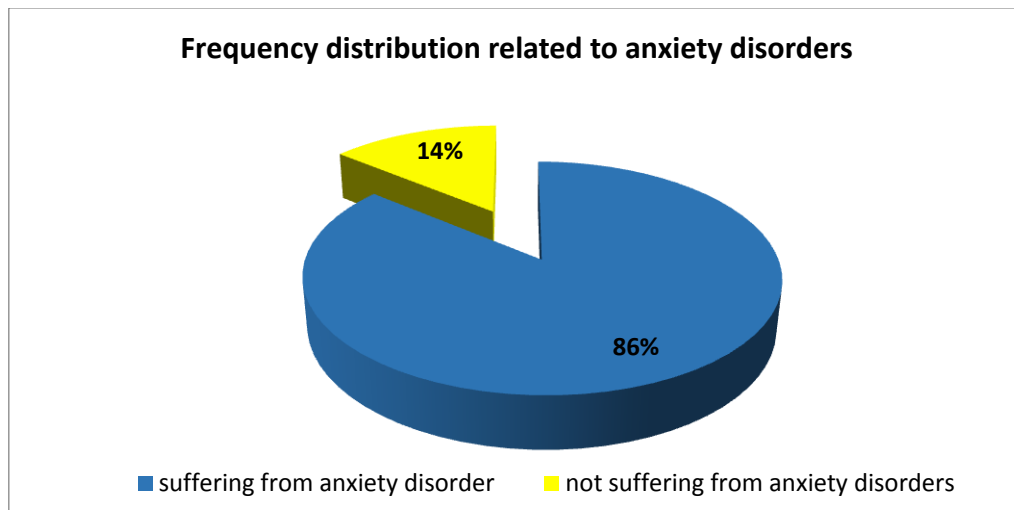


Figure 7: Frequency distribution of the studied patients related to anxiety disorders

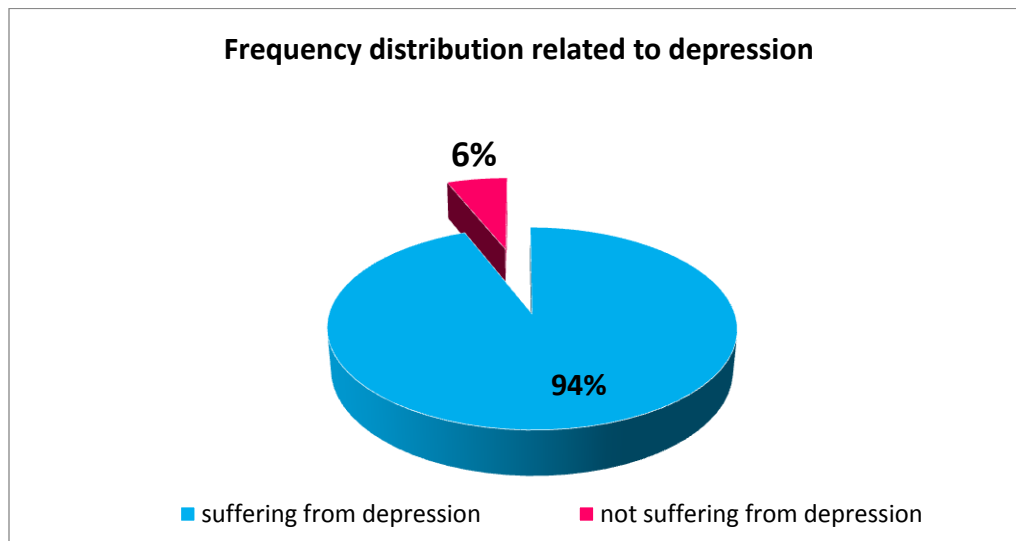


Figure 8: Frequency distribution of the studied patients related to depression

As regards to frequency distribution of studied sample according to type of anxiety disorder table 3 showed that, (98%, 97%, 94%, 89%, and 62%) of the studied sample suffering from, significant somatic symptoms, generalized somatic anxiety disorders, separation anxiety disorders, social anxiety disorders, school significant avoidance respectively.

Table 3: Frequency distribution of studied sample according to type of anxiety disorder (n=100)

Items	Suffering from disorder		Not suffering disorder	
	No	%	No	%
- Significant somatic symptoms	98	98	2	2
- Generalized somatic anxiety disorders	97	97	3	3
- Separation anxiety disorders	94	94	6	6
- Social anxiety disorders	89	89	11	11
- School significant avoidance	62	62	38	38

Table 4 reveals that, there is a statistically significant correlation between follow-up and depression where ($r=0.22$ at $p=0.02$). Also, there is a statistically significant correlation between mother job and depression where ($r=0.46$ at $p=0.05$).

Table 4: Correlation between socio-demographic characteristics and depression of the studied sample

Items	Depression	
	r	p-value
-Age	0.07	0.46
Duration of illness	-0.04	0.44
Follow up	-0.22	0.02*
Educational achievement	0.07	0.46
Educational level	0.05	0.59
Father education	0.005	0.95
Mother education	0.008	0.14
Father job	0.002	0.98
Mother job	0.46	0.05*

*Correlation is significant at the $P = 0.05$

Table 5 reveals that, there is a statistically significant correlation between educational achievement and anxiety level where ($r=0.05$ at $p=0.01$). Also, there is a statistically significant correlation between father education and anxiety disorder where ($r=0.26$ at $p=0.008$).

Table 5: Correlation between socio-demographic characteristics and anxiety level of the studied sample

Items	Anxiety disorders	
	r	p-value
-Age	-0.003	0.97
Duration of illness	0.04	0.69
Follow up	0.11	0.27
Educational achievement	0.05*	0.01
Educational level	0.009	0.93
Father education	0.26*	0.008

Mother education	0.14	0.16
Father job	0.05	0.59
Mother job	0.11	0.23

*Correlation is significant at the $P \leq 0.05$

DISCUSSION

Results of the current study showed that, the mean age of the studied children were (8.63±2.78), with no statistically significant correlation in relation to anxiety and depression, this may interpreted as all of them are affected by the same level but doesn't reach the significant value, and it may be related to that hemophilia A and B are sex linked diseases, and the genes responsible for the synthesis of factor VIII and factor IX are located on the X chromosome. The results in the same line with, Valizadeh, et al, (2015) who indicated that, the mean age of children with hemophilia was 11.6 ± 2.5 years [18]., and a study by, Atwa, et al, (2017) who indicated that, the mean age of hemophilic children was 7.8 ± 3.8 years [19].

Regarding educational achievement of the studied sample, the study results reported that, forty eight percent, and twenty two percent of the studied sample achieve good and pass respectively, and twenty percent of them were fail in the school and only three percent were excellent in academic achievement, with significant correlation in relation to level of anxiety which may be interpreted as their presence among large group of children in school with excessive instructions related to their disease in relation to playing, eating, and other life activities. Moreover, hemophilia as a chronic disease which has negative impact on school achievement, due to frequent absenteeism and repeated hospital visits one time and more monthly and school drop-out of school due to complication. The study results are in agreement with, Dharmarajan, et al, (2012) who found that, children with hemophilia, on an average have lost 0 to 50 days of school days due to bleeding [20]. Moreover, the study in the same line with, Cutter, et al, (2017), and Forsyth, et al, (2014) who stated that, children with hemophilia missed more days of school and tended to have lower academic achievement, and have negative impact of hemophilia on school-related activities [21, 22].

In the same line with, Miller, et al, (2011) who revealed that, hemophilia can lead to emotional, behavioral, and cognitive problems [23]. Children with hemophilia confront extreme stress, deprivation and serious limitations associated with their disease [5]. The study results are supported by, Firoozi, (2017) who revealed that, perceived stress can interfere with brain functions and may result in emotional dysfunction. Moreover, children with hemophilia would be more absent from the school due to occasional bleeding episodes. On the other hand, physical limitations prevent them from participating in school activities and do their homework same as their healthy peers. This could explain their poor academic achievement [10]

The current study results indicated that, more than half of studied sample follow up accompanying their mothers, it may related to most of children's mother were housewives, and mothers who take responsibility for children health which is a common culture concept in

Eastern countries especially Egypt, with statistically significant correlation with depression, this may be interpreted as weekly or monthly follow up is very exhausting for the children which affect their mood and emotional status. Moreover, most of the children's mother not work this may be related to their responsibility a main family caregivers and provide comprehensive care for children's health.

The current study results supported by, Toledano, and Domínguez-Guedea, (2019) who showed a greater percentage of female family caregivers (81.7%) than male family caregivers (18.3%) in the total number of families with hemophilic children [24]. Moreover, Bourke-Taylor, Howie, and Law (2012) indicated that, mothers of children with hemophilia were less likely to work fulltime [25]. In addition, Spencer, (2014) indicated that, mothers in families caring for children with bleeding disorder were 1.5 times more likely to be not participating in the work force [26].

The current study results showed that, near half of the studied sample their mothers and fathers have middle educational level, with significant statistically correlation between fathers educational level and anxiety among the studied sample, this may be interpreted as increasing the level of education of parents increase their fear, and restrictions in applying the instruction related to their hemophilic children playing, and other life activities which make their children very anxious, expressing somatic complaints, thought problems, attention problems and aggressive behavior, internalizing and externalizing problems and generally behavioral-emotional problems. The study results in the same line with, Al-Zubeidi, et al, (2019) who stated that, (32.5%) of the hemophilic children fathers levels of education is graduate, (27.5%) of hemophilic children mother's levels of education is able to read and write, and (47.5%) of the study sample present with a middle socio-economic status [27].

The current study results revealed that, most of the studied sample suffering from anxiety disorder, including significant somatic symptoms, generalized somatic anxiety, separation anxiety, social anxiety, and school significant avoidance.

The study results are in the same line with, Witkop, et al, (2017) who stated that, children with hemophilia and a history of bleeding, reporting pain were more likely to experience anxiety and depression, worse health status, and functional impairment [28]. Also, the study results are in agreement with, Witkop, et al, (2015) who disclosed that approximately half of hemophilic children have anxiety related to pain` and bleeding [29]. Another study by, Kodra, et al, (2014) who revealed that, 43% of hemophilic children have anxiety [30]. Moreover, Abali, et al, (2014) concluded that, anxiety levels of children with hemophilia were rated as high [31]. Moreover, Froze, (2017) indicated that, children with hemophilia are less prone to socialization because they are afraid of participating in group activities [10].

The current study results indicated that, most of the studied children suffering from depression, this may be related to that, children with hemophilia have, activity limitations such as, sitting on the sidelines while classmates play sports or engage in other off-limit activities can contribute to depression in children with bleeding disorders. Moreover, children with hemophilia are not

allowed to participate in activities or whose parents are overly protective may be annoyed by peers. Moreover, the hemophilic children may be seeming them-selves different, may be self-conscious about bruises, needle marks, or swollen joints.

The study results are supported by, Abali, et al (2014) who concluded that, depressive symptoms are commonly seen in hemophilic children [31]. Also, Hassan, et al, (2011) revealed that, only one-third of hemophilic children reported not being depressed [11]. Moreover, Forsyth, et al (2015), and Iannone, et al, (2012) who revealed that, depression has been reported in 37%-43% of hemophilic children [32, 33].

The current study results are in agreement with, Franchini, and Mannucci, (2012) who indicated that, hemophilia had a significant effect on family lives, educational issues, school and traveling plans. Most of them felt frustrated and expressed anger against the disease [34]. Moreover, Valentino, et al, (2012) reports, children with hemophilia showed more problems in internalizing and anxiety/depression disorders. Children with hemophilia showed symptoms of depression more commonly compared to healthy children [35].

Current study results in the same line with, Manikandasamy, et al, (2017) who indicated that, children with hemophilia are reported to have a high burden of emotional difficulties and have been reported with conditions like lower self-perception and depression [36]. Studies have reported that children with hemophilia are less joyful, less open and caring [37].

Over-parenting, lack of social learning and negative self-perception are involved in emotional problems (as a psychological factor). Children with hemophilia are less prone to socialization because they are afraid of participating in group activities. They are at increased risk for rejection by peers. So, social isolation may be a trigger for depression and anxiety (as a social factor). On the other hand, the child may feel anger followed by environmental and social deprivations. It would be expressed as aggressive behavior and conduct disorder [10].

CONCLUSION

The current study results concluded that, hemophilic children are suffering from anxiety disorders, including significant somatic symptoms, generalized somatic anxiety, separation anxiety, social anxiety, and school significant avoidance. Moreover, hemophilic children are experiencing mood disorder includes depression. In-addition the current study results revealed that, school achievement is affected due to frequency of absenteeism because of frequent bleeding and a lot of instructions regarding school activities and other daily living activities.

RECOMMENDATIONS

1. Psychological interventions for hemophilic children accompanying pharmacological intervention is essential.
2. Intervention school and family programs for hemophilic children
3. Replication of the study using a larger sample to generalize the results

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