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Knowledge, Attitudes and Practices of Preventing Complications Among Adolescents With Severe Hemophilia

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Background: Appropriate management of chronic conditions requires full knowledge of the situation-related complications and preventive behaviors, which can improve or eliminate these complications. It is also essential to evaluate treatment methods regularly, with respect to the features of each social group and the available resources.

Objectives: This study aimed to evaluate the level of knowledge, attitudes and practices of adolescents with severe hemophilia, with regard to the prevention of related complications.

Patients and Methods: A pilot study was conducted in a hemophilia center (East Azerbaijan, Iran). In total, 40 adolescents with severe hemophilia were included in the study. The Nazzaro et al. questionnaire was conducted using a telephone interview. Data were analyzed using SPSS (version 13). Results were expressed as frequencies, means and standard deviations.

Results: A relatively large proportion of the subjects (46% and 64%) had not been informed of the transmission methods of hepatitis B and C, respectively. Bleeding episodes (61%) and joint disorders (26%) were the main concerns for the majority of subjects. Less than half (38%) of the respondents had had an experience of managing a bleeding episode within a one hour period. Half of the subjects were involved in vigorous activity, which ranged from one to more than five days per week, and only 37% of the subjects participated in moderate physical activity for more than 5 days per week.

Conclusions: The current study highlights the need to improve the level of knowledge, attitudes and practices of adolescents with severe hemophilia. The prevention of complications, can be assisted by providing; education, skill sessions and group discussions.

*Keywords:*Complications; Prevention and Control; Knowledge; Attitude; Adolescents

1. Background

Hemophilia is the most common hereditary coagulation factor deficiency. This condition is an X-linked disease, and it is induced by a defect of factor VIII (hemophilia A) or factor IX (hemophilia B) (1). Clotting deficiency disorders are not confined to a particular region and can be found throughout the world. It is essential to evaluate treatment methods regularly, with respect to the features of each social group and accessibility of resources (2). Hemophilia impacts approximately 400 000 people worldwide (3). In Iran, this disorder affects about 4 939 people, of whom 4 063 have type A, and 876 have type B (4). The East Azerbaijan Province is estimated to have 292 males affected by hemophilia A and B (5).

People with bleeding disorders can live healthy and effective lives. If left untreated bleeding disorders, specifically hemophilia, can lead to disabling pain, acute joint injury and lethal internal bleeding (3). Bleeding contributes to the progressive deterioration of joints and muscles and this affects patients' well-being and their everyday activities (6, 7). Early treatment of severe hemorrhage episodes is necessary to reduce long-term complications. Equally, non-pharmacologic and pharmacologic strategies can be utilized in the treatment of hemophilia (8). Prior to the 1990's, most adults and teens with hemophilia and other bleeding disorders who required a transfusion of blood components or plasma-derived clotting factor concentrates, developed hepatitis infections. In the 1990's considerable advances in transfusion safety occurred, most notably the development of a sensitive hepatitis C screening test in donors (9). The hepatitis C virus

Implication for health policy/practice/research/medical education:
The present pilot study highlights the need for continuous improvements in the knowledge, attitudes and practices of adolescents with severe hemophilia, in order to prevent complications. The results of this study highlight important information that would assist in the comprehensive care of hemophiliac patients. This information can be conveyed to health care providers, especially in hemophilia care services, to enhance the ways in which they provide support for adolescents with severe hemophilia.

(HCV), which has infected nearly 90% of hemophiliac patients, is also associated with a high mortality rate (10). It is estimated that among the hemophiliac population of Iran, 2 750 people are affected by HCV, and approximately 49 by HIV (4). Recent advances in blood product processing and its applications have virtually eliminated the risk of transmission for most pathogens, including HIV, and hepatitis B and C. However, the safety of blood products can never be completely guaranteed (10).

Adolescence is a life stage full of questions and concerns about individuality, self-esteem and communication (11). The concurrent physical, psychological, social and sexual changes experienced by male adolescents, complicate the disease-related challenges encountered by health care providers, parents and the adolescent patients themselves (12). Based on published statistics, adolescents comprise nearly half of the hemophiliac population in Iran (4). Effective management of this chronic condition requires full knowledge of the situation-related complications and preventive behaviors which can improve or eliminate these complications (11). Previous studies have revealed that nearly 50% of adolescents with chronic diseases do not comply with care recommendations (13). It is also known that adolescents are more likely to decrease or discontinue prophylaxis (14-16); which is probably because they are primarily oriented in the present and less concerned about long-term health risks, than their parents or adults with the condition (17).

To ensure accountability and the active participation of adolescents with hemophilia, it is not only critical awareness of the nature of their disease which is important, but also motivation, positive attitudes and learning skills, as the prevention and control of symptoms are essential and these all require comprehensive plans (18). However, a formalized training process for adolescents, in which self-care interventions to manage and control this disease and related complications can be taught, has not yet been developed (11). Medical care experience and extensive investigation have indicated the need for continuous improvement of information and educational plans, directed towards adolescents with bleeding disorders (13). In Iran, studies about hemophilia are more concerned with joint injuries, medication therapies and the incidence of blood-borne infections (19-24). One study has been conducted on quality of life and adherence to treatment (18, 25). However, there has been little attention paid to knowledge, attitudes and behaviors of patients towards this disease, especially in adolescence.

2. Objectives

The present study aimed to evaluate the level of knowledge, attitudes and practices of adolescents with severe hemophilia on the prevention of related complications. The findings of this pilot study could be useful in developing a national prevention program.

3. Patients and Methods

This study was an analytical cross-sectional pilot research. The target population was adolescents with severe hemophilia who attended a hemophilia center, in the East Azerbaijan Province, Iran. The inclusion criteria consisted of; age 11-20 years, diagnosis of severe hemophilia A or B, history of previous treatment, access to a phone, interest in participating in the present study with a telephone interview, ability to answer questions (physically and mentally), and to understand and speak Azeri or Persian. One of the main reasons for using telephone interviews was that the subjects lived in different cities with a wide geographical distribution. A total number of 40 subjects were enrolled in the study, which was based on the previously mentioned criteria (all of the adolescents included met the inclusion criteria). Informed, oral consent was obtained from each subject and their parents, prior to the adolescent's participation in the telephone interview. Following a broad literature review, the researchers used the Nazzaro et al. questionnaire (11). The survey's objectives were to assess: (1) compliance with recommended prevention behaviors, (2) self-management of hemophilia, (3) knowledge, beliefs and practices related to dealing with joint disease and infections, and (4) the perceived value of the hemophilia treatment center's (HTC) services. A total of 7 nursing faculty members assessed the instrument intelligibility as well as clarity of its content. Revisions were made based on their suggestions. It was validated through content validity and the reliability was calculated using a Cronbach's alpha reliability coefficient ($\alpha = 0.72$). Data were collected over a period of two months in 2010 and analyzed using a SPSS statistical package (ver. 17.0). Results were expressed as frequencies, means and standard deviations.

4. Results

Among the 40 subjects aged from 11 to 20 years, 23% were 13-15 years-of-age, 49% were 16-18 years and 28% were 19 years or more. The mean age of the participants was 15.90 $\pm$ 2.7 years and all of the respondents were male. From the total number of 40 subjects, 51% of the adolescents were the first or second child in the family. The majority of the participants named events such as falling down and associated outcomes, which were important in the diagnosis of their disease. Four participants (10%) were infected with hepatitis. To clarify the level of their knowledge of the different types of hepatitis, the participants were initially asked whether they had ever received information about hepatitis. A total of 42% reported that they had received such information. They were then asked to rate their general knowledge of hepatitis on a scale of one to ten, in which ten denoted a very high level of knowledge.

Almost 12% of the subjects rated their knowledge of hepatitis as high (rating of 8 or above), 30% as moderate (rating of 4-7), and nearly 58% as low (rating of 3 or below). Furthermore, the participants were asked specific

questions about the methods of hepatitis B and C transmission. Approximately, 46% and 64% of the subjects did not know the transmission methods of hepatitis B and C, respectively. The main concerns for most of the subjects are displayed in Table 1. Later the level of these concerns was confirmed using a 10-point rating scale. The subjects were asked to rate the degree to which each complication was a preventable concern, from one to ten (1 = not at all preventable, 10 = extremely preventable). The average score for the main disorders is shown in Table 1.

A group of questions was developed to identify the subjects' preventive practices, which could decrease or avoid hemophilia complications, and whether the participants were involved with these practices. A total of 38% of subjects stated that they utilized clotting factor treatment preventively, either in an arranged program, or prior to physical activity, sports, and heavy exercise, or they underwent the usual treatment with clotting factors. Roughly 16% of the respondents reported that they avoided or limited heavy physical activity and almost 16% mentioned that they used an ice bag when bleeding occurs. Nearly 5% reported that they exercised as a preventive tool and 5% of the respondents stated that they avoided exercise. Approximately 3% indicated that they did not know whether or not they were being treated with some form of prophylaxis, while another 17% reported adjustment of activities, rest and avoiding the use of sharp tools and participating in dangerous activities. Respondents were asked specifically how rapidly they usually treated a hemorrhage episode. They were asked to select the category that best depicted the timing of their self-management, ranging from within one hour, to longer than six hours after the incident of a bleeding episode. Fewer than half (38%) of the respondents reported treating a bleeding episode within one hour (Table 2).

A group of questions were developed to identify barriers to self-management in the early time period (i.e. management within 1-2 hours from the start of a bleeding episode). In total, 41% reported that they did not have the clotting factor with them at the time of the episode, and some of the adolescents (23%) stated that they had not recognized such episodes and thus delayed managing them. Almost 10% indicated that they did not believe the episode was severe enough to require management. These statements were the most common replies among the respondents. The most common hemorrhage episodes resulting in uncontrolled bleeding were due to damage to the mouth and teeth, like dental extraction and oral surgery, and also accidents.

Adolescents were asked how many days in the last week they had been involved in high or moderate energy consuming activities. Respondents were offered five items: never, 1 day or less, 2-3 days, 4-5 days, and more than 5 days, to describe the extent to which they participated in vigorous and moderate activities in the previous week. Half of the subjects reported being involved in vigorous activities, ranging from one to more than five days, while less than half of the subjects (37%) mentioned, more than five days, participating in moderate physical activity. Table 3 shows the numbers of days the adolescents participated in heavy and moderate activities during the previous week.

Table 1. Hemophilia Complications of Primary Concern [a]

	Sample, %	Point's Average
Bleeding episodes	61	7.43
Joint damage	26	8.83
Unknown	13	–

[a] no data is available.

Table 2. Usual Timeliness of Self-Treatment of Bleeding Episodes

Timeliness of Self-Treatment, y	Sample, %
≤ 1	31
≤ 3	40
≤ 6	9
> 6	15
Unknown	6

Table 3. Number of Days Participating in Heavy and Moderate Activities in the Previous Week

Number of Days	Vigorous Activity Sample, %	Moderate Activity Sample, %
Never	50	7
≤ 1	28	19
2-3	19	30
4-5	0	7
> 5	3	37

5. Discussion

Effective preventive interventions for hemophilia complications should be evidence-based and dedicated to special target populations (11). To achieve this goal requires assessment of a sample from the target population and utilizing a patient-centered approach, which is also important (11). Therefore, the aim of this study was to determine the current level of knowledge, attitudes and behaviors, especially those concerning prevention, in adolescents with hemophilia. Studies have shown that patient training and care, through hemophilia treatment centers, can eliminate many of the barriers that prevent participants from adherence to recommended therapies (26).

Another significant issue for people with hemophilia and bleeding disorders is hepatitis. However, our data determined that almost 64% and 46% of the subjects did not know the transmission methods of hepatitis C and

B, respectively. The participants in this study were born between 1990 and 1999. Heat-treated factor became available in 1985 for FVIII products (to treat hemophilia A or factor VIII deficiency), and in 1987 for FIX products (to treat hemophilia B or factor IX deficiency) (11). Nevertheless, some people (four people) were infected with hepatitis. Although not everybody at risk had been exposed to the viruses, it is essential that all adolescents with hemophilia understand the transmission modes of these infections and the potential threats of hepatitis A, B, and C and HIV. Furthermore, other essential information includes; sexual activity, and behaviors such as experimenting with illegal drugs, especially throughout the development of maturity (27). Although some of the adolescents had been given information about hepatitis, the survey showed that the actual level of knowledge about hepatitis was not high (average score on a scale of 1 to 10 was 5.9). In spite of the importance of understanding the different types of hepatitis, and despite the risks of hepatitis B and C infections in these adolescents, a large number of these young people did not understand how hepatitis C is transmitted. This finding points to the essential need to educate adolescents with hemophilia about blood transmission of hepatitis B and C.

A frequent long-term complication of hemophilia is irreversible damage to the joints induced by recurrent hemorrhagic episodes (28, 29). The results of the current study showed that 'bleeding episodes' and 'joint damage', were the top concerns among the participants. A large number of respondents believed that using clotting factor treatment preventively, either on a regular program, or before physical activity and different types of exercises, or undergoing regular treatment with blood products in a bleeding episode, was important. In a study conducted by Fromme et al. it was concluded that attitudes toward exercise have improved, most likely due to better medical treatments (30). The fact that more than one third of the respondents stated that they did not have clotting factor with them during the occurrence of episodes, could be associated with their concerns. On the other hand, some of the subjects stated that they did not recognize such episodes and thus delayed treatment. In addition, one of the reasons they delayed the treatment was that they did not identify it as necessary. Similar findings were reported by Nazzaro (11).

In this regard, Mehramiri et al. showed that supplying resources to obtain a higher level of understanding and encouraging adolescents could be helpful in developing more appropriate attitudes towards their health and overcoming disease-related problems (31). Two significant preventive factors against hemophilia-related joint injuries, are physical activity (exercise) and early treatment of a hemorrhage episode (within an hour), or treatment with prophylaxis (11).

According to the results of a study by Engelbert et al. children with hemophilia have a reduced level of aerobic activity capacity, compared to normal children (32). In addition, patients with hemophilia are at increased risk for the development of low bone density, type II diabetes, metabolic syndrome, depression, obesity and hemophilic arthropathy (33). Results of the present study determined that only about one-third of the participants mentioned participation in moderate physical activity for more than five days and half of them reported engagement in vigorous activity for one to more than five days per week. Physical activity is important for all adolescents, but disease-related functional deficits, may necessitate particular consideration in selecting a suitable exercise which decreases the possibility of injury and matches the patient's ability and interests (12). These adolescents may forget about their condition and perceive themselves as being similar to their healthy peers and siblings (34), and able to fully participate in all the customary activities of adolescence (35). Advanced therapies for the hemophilia population are aimed towards sports and a wider variety of recommended exercises (30). A number of people with hemophilia avoid exercise as they believe it may result in bleeding episodes (11). However, Ross et al. showed that regular attendance in high-impact physical activity, supported by adult coaching and supervision, did not appear to raise the risk of a progression of joint bleeding, or joint injury in school-aged children with severe hemophilia, if they continued routine replacement of prophylactic factor (36). Physical activity is encouraged as a preventive agent, and abstaining from physical activity is in fact only suggested once a bleeding episode has taken place (11, 37). Only 38% of the subjects indicated that they used clotting factor treatment preventively, either on a regular schedule or before physical activity, sports and vigorous exercise, or undergoing usual treatment with blood products. Many of the young people reported that they did not have access to clotting factor at the time the event occurred. Adults with hemophilia, who did not have free access to blood products and sufficient treatment in the early hours in life, generally have observable joint abnormalities and chronic pain (11). Prophylaxis is now considered an important therapeutic option in young children with severe hemophilia for the prevention of end-stage joint disease and enhanced quality of life (38, 39). On the other hand, prophylaxis programs are associated with the excessive use of clotting factors and these products are expensive. However, patients in developed countries are usually supported with this method (40). In spite of economic limitations, a developing country like Iran continues to optimize its resources for hemophilia care (41).

Some of the subjects stated that they did not recognize the urgency of such episodes and thus delayed treating them, while less than half of the participants reported managing a bleeding episode in the recommended time period. Quick diagnosis and treatment of joint damage is very important, as the degree of cartilage damage induced by hemosiderin deposits increases over time (42).

As children grow, they increase their hemophilia specific knowledge and skills sets, in addition to their

attitudes and life skills, thus enabling them to improve their understanding of the lifestyle issues which influence their health (35). In young males with hemophilia, this includes an understanding of complex bodily functions, including; why bleeding occurs, when it is most likely to take place, when, why and how to treat bleeding, and when to look for further information and assistance (15). Therefore, when designing an effective prevention method for chronic diseases, it is important to consider the specific condition and developmental stage of the target population (11). In this regard regular training sessions based on a needs assessment, should include: individual training, skill development, teaching methods such as demonstrations and using role models, along with group discussion to enhance their knowledge, attitudes and skills.

One limitation of our study was its small sample size. Another limitation was the intrinsic unreliability of the answers, as their accuracy may have been compromised because they were administered by phone interviews, especially in the lower age range of adolescents.

The results from this study provide important implications towards comprehensive care of patients with hemophilia. This information can be conveyed to health care providers especially in hemophilia care services, to enhance the ways in which they provide help for adolescents with severe hemophilia. Additionally, programs may be developed in order to help adolescents meet their self-care expectations. In fact, the most important implication in practice from this study is for health care providers, particularly in HTCs and hemophilia centers, as they should be more aware of young people's needs during their interactions, in addition to providing necessary information and evaluating related behaviors. The present pilot study highlights the need for a continuous improvement of knowledge, attitudes and practices of adolescents with severe hemophilia in order to prevent complications. This can be obtained by providing essential knowledge, particularly in relation to lifestyle and appropriate activities, familiarity and access to medicines and how to use them, awareness of viral infection transmission, preventive strategies and related behaviors.

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Authors' Contribution

Leila Valizadeh and Fahimeh A, Hoseini were responsible for the study conception and design, Solmaz Fallahi and Mina Ramezan Behtash performed the data collection, Leila Valizadeh and Fahimeh A, Hoseini performed the data analysis, Fahimeh A, Hoseini was responsible for the drafting of the manuscript, Leila Valizadeh and Fahimeh A, Hoseini made critical revisions to the paper for important intellectual content and Vahid Zamanzadeh supervised the study.

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