Needs of patients with hemophilia: Suggested clinical pathway

Abstract

Patients with hemophilia have physical, psychological and social needs, therefore the aim of the current study is to explore needs of patients with hemophilia and suggest clinical pathway for these patients. To fulfill the aim of this study an exploratory descriptive research design was utilized. A purposive sample of 30 patients with hemophilia was selected over a period of 3 months from hematology units in a governmental hospital. Two tools were utilized (I) personal and medical data, (II) needs of patients with hemophilia. The study findings revealed that 43.3% of the studied patients had hepatitis C virus and 26.6% of them had deformity in the shape and functions of knees joints. Only 6.7% of the studied patients received information about their disease from heath team members. 90% of the studied patients mentioned that; the medical team did not receive them when they were admitted to the hospital and all them didn't receive hospital orientation, did not engage in their treatment plan and did not perform any kind of exercises and 90% of them did not find the medical team when needed. 96.7% of the studied patients were not satisfied with the medical services provided to them. Based on the results of the current study it could be concluded that patients with hemophilia have physical, psychological and social needs. Application of clinical pathway may provide comprehensive care for patients with hemophilia.

Keywords: needs, patients with hemophilia, clinical pathway

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Background

Hemophilia is the most common inherited bleeding disorder characterized by decreased function or absence of factor VIII (classic hemophilia or hemophilia A) or factor IX (Christmas disease or hemophilia B). Hemophilia is a male disorder, yet females with hemophilia are rarely seen in communities but they are carriers. Hemophilia A and B are inherited as X-linked genetic recessive disorder but 30% of patients have no family history of the disease and they usually have spontaneous new mutation (Christmas disease or hemophilia B) [1].

Hemophilia A is four times more common than hemophilia B, this account for about 80 percent of the total number of patients with hemophilia. Hemophilia affects people from all races. It is a lifelong disorder with three phenotypes (severe, moderate and mild) that correlate with factor VIII (FVIII) levels in plasma. From 5 to 40 percent of normal clotting factor is considered mild, 1 to 5 percent is moderate, and less than 1 percent is severe. Absence of clotting factors increase bleeding time after minor injury or cause spontaneous bleeding in patients with severe disease especially in patients' joints [2-4]. These complications of hemophilia include physical complications such as deep internal bleeding, approximately 80%-90% of bleeding episodes in hemophilia occur in the musculoskeletal system, especially in the large synovial joints (elbows, knees, ankles, hips and shoulders). Other bleeding episodes can occur at any part of the body such as hematuria and epistaxis [5,6].

Other physical complications that may occur for patients with hemophilia include joints damage, infection from blood or blood product transfusion such as hepatitis B, C and AIDS, adverse reaction to clotting factor treatment or blood product infusion, and antibody formation to factor products known as inhibitors. Psychosocial complications that may occur including fear, anxiety, stress, depression, lack of interest, social isolation, and inability to perform role, and feeling of dependency [7].

Hemophilia is treated with replacement therapy (Clotting factors) that can be derived from human blood (Clotting factor concentrates)

or synthetically produced in a laboratory (recombinant clotting factors) which is considered the treatment of choice to reduce the risk of transmitting infections that are carried in human blood. Some patients will need regular replacement therapy (prophylactic therapy) in order to prevent bleeding. Others receive demand therapy that is given only after bleeding begins and remains uncontrollable [3,8].

Patients with hemophilia have physical, psychological and social needs, these needs include; information about their disease and how to deal with it, physiotherapy, psychological and social support and counseling, nutritional advice, medication regimen and follow-up, home therapy, and occupational advisor. Hematology nurses play a crucial role in providing comprehensive care to these patients based on assessing patients and their families' needs to promote optimal physical, psychosocial and emotional health, and to minimize complications from bleeding and treatment as well as improve quality of life while decreasing morbidity and mortality rate [9-11].

The World Federation of Hemophilia (WFH), [12] recommends that; the wide range and changing needs of patients and their families are best met through a multidisciplinary comprehensive care team that includes hematologist, hematological nurse, surgeon, physical therapist, psychologist, nutritionist, and social worker, with access to additional specialists as needed in accordance with accepted protocols that are practical and national treatment guidelines or clinical pathway. Suggested clinical pathway provides comprehensive health care for patients with hemophilia and their families based on patients' needs to ensure that all important issues are involved. Also clinical pathway has been recommended to improve clinical outcomes, decrease mortality rates, and improve cost-effectiveness in health care settings [13]. Therefore, the aim of the current study is to explore needs of patients with hemophilia and suggest clinical pathway for those patients.

■ Significance of the study

World widely, there are more than 400,000 people with hemophilia; about1 in 5,000 males has hemophilia [4]. According to the World Federation of Hemophilia (WFH), the estimated number of hemophilic patients in Egypt is around 7500,000 [12], another search concluded that; in Egypt around 8,300 patients with hemophilia [14]. Hemophilia is a serious lifelong disease, and patients must depend on infusions of clotting factors several times per week to prevent bleeding throughout their lives, although effective treatments do exist, but they are expensive [15,16].

Patients with hemophilia can be hospitalized by severe spontaneous life threatening episodes of bleeding. This bleeding can be fatal if it cannot be stopped or if it takes place in the brain or another vital organ. Moreover, hemophilic patients are prone to many complications. hemophilia not only affects patients by its clinical consequences, but also causes a great economic problem to health care systems due to costs of frequent hospitalizations, follow up visits and drugs in addition to costs due to decreased productivity of the affected individuals at work and schools therefore, the need for comprehensive care is very necessary for these patients. The comprehensive management plan should be individualized and adapted in accordance with patients' changing needs.

Review of literature shows few nursing studies about hemophilia in general. Also, there is scarcity of researches applied to study the needs of patients with hemophilia as well as developed clinical pathway for these patients in Egypt. Although two recent studies were conducted to examine the impact of clinical pathway on patients' outcomes revealed that clinical pathway proved to be an effective approach to decrease physical complications, hospital cost, and length of hospital stay and improve patients' outcomes [17].

Therefore, this study could be beneficial in providing health care providers especially nurses with data base regarding the needs of patients with hemophilia that utilized by health care professional as well as suggest clinical pathway for those patients to maintain cost effectively and reduce unnecessary delays in care, decrease mortality rate for patients with hemophilia. Also, this study might have a positive reflection on patients' general health status during and after hospitalization, through improving patients' quality of care by reducing the physical and psychological complications. Furthermore, this study may contribute some evidential data to help health team member specially hemophilia nurse to integrate it in the care of patients with hemophilia. Data derived from this study may provide a nucleus for further qualitative and quantitative studies in this field.

■ Aim

The aim of this study was to:

1. Explore the needs of patients with hemophilia
2. Suggest clinical pathway for patients with hemophilia

■ The research questions

To fulfill the aims of the current study the following research questions were formulated:

1. What are the needs of patients with hemophilia?
2. What is the suggested clinical pathway for patients with hemophilia?

■ Research design

An exploratory, descriptive research design was used in the current study.

■ Setting

This study was conducted in different hematology units at governmental hospitals. These units were established to provide treatment to all types of blood diseases for adults.

■ Sample

A purposive sample consisting of 30 patients with hemophilia were included. This number was calculated using a power analysis and recruited to this study according to the following inclusion criteria.

a) Conscious adult male patients

b) Had an age range between 18 to 55 years

c) Able to communicate through talking

d) free from mental problems or any cognitive impairments that would prevent them from sharing their self-experiences

e) Agreed to participate in the study

f) Able to sign a consent form

Tools of Data Collection

The researchers used two tools to assess need of patients with hemophilia which include; personal and medical data (tool 1), which includes; patient's code, age, gender, place of residence, type of hemophilia, date of, first time the symptoms of disease were discovered, presence of comorbid diseases etc. (tool 2) designed to assess patients' needs and their suggestions to improve quality of their care which include main source of patients' information about disease, availability of health team members when needed, availability of patients' orientation for hospitalization, application of exercises during hospitalization, and their suggestion to improve care provided to them.

Tools Validity and Reliability

Face and content validity of the study tools were tested by panel of three experts' faculty members in Medical Surgical Nursing field from Faculty of Nursing Cairo University. Reliability of the study tools were tested using test-retest=(0.8).

Pilot Study

A pilot study was conducted on 10 patients with the same inclusion criteria to ensure the feasibility of the study and the study tools for data collection, as well as to examine issues related to the research design, time required to fill out the sheet. Based on feedback taken from the pilot study there were no modifications done in the study tools. The pilot study was included in the study sample.

Ethical Consideration

An official permission was obtained from hospitals administrators to conduct the study. The purpose and nature of the study as well as the importance were explained to the patients who met the inclusion criteria. Signed consent was obtained from the patients who choose to participate in the study. Also, anonymity and confidentiality were assured through coding the data. Patients were assured that participation in this study was voluntary and they have the right to withdraw from the study at any time without penalty.

Procedure

The study was conducted on four phases; assessment, planning, implementation, and evaluation phase. Assessment phase involves collecting data through reviewing the literature dating back to at least 5 years using scientific data base. Planning phase; based on the outcome of the assessment phase, final format of the study tools were developed. Final decision about time, frequency, of patients' interview was develop. Implementation phase; firstly, the researchers communicated with the head nurses of different haematology units to identify patients with haemophilia. Then; the researchers conducted

an initial meeting with each patient individually for 10 minutes, to explain the nature of the study and take the initial agreement. Then; each patient who were met the inclusion criteria for the study was approached individually for 30-45 minutes by the researchers to collect personal, and medical information (tool 1) as well as to collect data about needs of patients' with haemophilia (tool 2). Data was collected over a period of 3 months. Evaluation phase; after finishing the collected data were analysed statistically to assess needs of patients with haemophilia and suggested clinical pathway for patients with hemophilia was developed.

Data analysis

Collected data was tabulated, computed, and analyzed using SPSS, version 20. Descriptive statistics including frequency distribution, percentage, means and standard deviations were use.

Data Analysis

■ Personal and medical information of the studied patients

TABLE 1 illustrates that; almost of two thirds of the studied patients are in age range between 28 to less than 38 years the mean age is (33.66 ± 0.583). All of them are male, 63.3% are married, 46% of them are self-employed and 26.7% have office work. Eighty percent of them reside in urban areas.

TABLE 2 describes that; 60% of the studied patients showed positive history of consanguinity type of hemophilia, and 90% of them had type (A) hemophilia. All patients reported that; the first time the symptoms of the disease was discovered by uncontrolled bleeding at circumcession. 26.6% and 16.7% of them reported having diabetes mellitus and renal stones respectively. 36.8% and 30% of the studied patient were had knees joints bleeding and epistaxis respectively.

TABLE 3 shows that; 43.3% of the studied patients reported having hepatitis C virus and 26.6% of them had deformity in the shape and functions of knees joints and 30% of them reported increase work absenteeism and insufficient income.

■ Needs of studied patients and their suggestions to improve medical care provided

TABLE 4 illustrates that; 40% of the studied patients receive information about hemophilia from other patients as a main source while only 6.7% of them received information from heath

TABLE 1. Frequency and percentage distribution of patients' personal information (n=30).

Item	No.	%	SD ± X
Age			
- 18-<28 years	4	13.3	33.66 ± 0.583
- 28-<38years	20	66.7	
- 38-<48 years	6	20	
Gender			
- Male	30	100	
- Female	0	0	
Marital status			
- Married	19	63.3	
- Single	8	26.7	
- Divorced	3	10	
Education			
- University degree	8	26.7	
- Secondary school diploma	9	23.3	
- Can read and write	7	16.7	
- Can't read or write	6	20	
Type of work			
- Office work	8	26.7	
- Self-employed	14	46.7	
- Student	3	10	
- Unemployed	5	16.6	
Place of residence			
- Urban	24	80%	
- Rural	6	20%	

TABLE 2. Frequency and percentage distribution of studied patients' medical information (n=30).		
Item	**No.**	**%**
Consanguinity		
- Positive	18	60
- Negative	12	40
Type of hemophilia		
- A	27	90
- B	3	10
The first time the symptoms of the disease were discovered		
- Uncontrolled bleeding during circumcision	30	100
Comorbidities		
- Hypertension	4	13.3
- Diabetes mellitus	8	26.6
- Renal stones	5	16.7
- Peptic ulcer	2	6.7
- Intestinal obstructions	1	3.3
- No	10	33.4
Common sites of bleeding		
- Knees joints	11	36.8
- Elbows joints	5	16.7
- Epistaxis	9	30
- Hematuria	2	6.6
- Oral bleeding	2	6.6
- Cephalic bleeding	1	3.3

TABLE 3. Frequency and percentage distribution of patients' medical information (n=30).		
Item	**No.**	**%**
Physical complications caused by the disease		
- Deformity in the shapes and functions of knees joints	8	26.6
- Deformity in the shapes and functions of elbow joints	4	13.4
- Deformity in the shapes and functions of ankle joint	3	10
- Atrophy in calf muscles	2	6.7
- Hepatitis C virus	13	43.3
Psychological, social and financial problems caused by the disease		
- Feeling of loneliness and insecurity	5	16.7
- Inability to do social activities and play the role	7	23.3
- Unavailability of clotting factors medications	7	23.3
- Increase work absenteeism and insufficient income	9	30
- Inability to fulfill the educational study requirements	2	6.7

Table 4. Frequency and percentage distribution related to needs of studied patients and their suggestions to improve medical care provided.		
Item	**No.**	**%**
What is the main source of your information about hemophilia?		
- Health team members	2	6.7
- Internet	8	26.6
- Reading	2	6.7
- Other patients	12	40
- Medical Charities	6	20
Did the medical team receive you when you were admitted to the hospital?		
- Yes	3	10
- No	27	90
Did any of the medical team orient you with the unit?		
- Yes	0	0
- No	30	100
Did the medical team engage you in your treatment plan?		
- Yes	0	0

- No	30	100
Did you perform any kind of exercises while you are in the hospital?		
- Yes	0	0
- No	30	100
Why? No one helped me to do so	30	100
Did you perform any kind of hobbies/leisure activities while you are in the hospital?		
- Yes	0	0
- No	30	100
Why? Because there is no one to encouraged me to do so.	30	100
Do you find the medical team when needed?		
- Yes	3	10
- No	27	90

TABLE 5. Frequency and percentage distribution related to needs of studied patients and their suggestions to improve medical care provided.

Item	No.	%
Are you satisfied with the medical services provided to you?		
Yes	1	3.3
No	29	96.7
What are your suggestions for improving medical services?		
- Raise health team members and community member's awareness about the disease	12	40
- Availability of clotting factors medication	6	20
- Establish specialized hospitals to provide comprehensive care for patients with hemophilia	2	33.3
- Use new modalities to treat hemophilia such as gene therapy		6.7

team members. 90% of the studied patients did not received by any one of the medical team upon admission to the unit and all of them did not getting unit orientation by medical team, and did not being engaged in their treatment plan, and 100% of them did not perform any kind of activities during hospitalization.

More than 90% of the studied patients were not satisfied with the medical services provided to them, 40% of them suggested that, raising health team members and community members' awareness about the disease and 33.3% of them suggested to establish specialized hospitals to provide them comprehensive care and only 6.7% of them suggested to use new modalities to treat hemophilia such as gene therapy **(TABLE 5)**.

Discussion

■ Section I

Hemophilia is a life-long disorder which creates profound physical, emotional, economic and social problems for those patients. These problems extend to society in general. In the present study, the majority of diagnosed hemophilia patients ninety percent were hemophilia type A and only ten percent were hemophilia type B. These results were in concordant with the results of study conducted by Tawfik et al . [18] findings of hemophilic patients in Assiut Egypt, also the study done by Speybroeck and Hermans [19] found that the majority of hemophilia cases eighty percent were hemophilia type A.

Positive consanguinity in the studied patients was present in sixty percent. These results were in agreement with the results of Al-Zubaidy [20] who carried descriptive study on patients with hemophilia in Al-Ramadi city, as positive consanguinity were reported in more than seventy percent and negative consanguinity in more than twenty five percent of hemophilic patients. Also these results were in agreement with the results of the study done by Borhany et al. [21] they showed a positive consanguinity marriage in Pakistan was more than sixty percent and negative consanguinity were more than thirty five percent of hemophilic patients. In the present study. All the studied patients reported that; the first time the symptoms of disease were discovered uncontrolled bleeding after circumcision. This result was in agreement with study conducted in Mansoura, Egypt by Tonbary et al. [22] who reported that; the common presenting symptom was bleeding following male circumcision.

Regarding the presence of other diseases/health problems, two third of the studied patients were had co-morbid diseases such as diabetes mellitus, renal stones and hypertension. This finding is

consistent with a study carried by Treil [23] who reported that; patients with hemophilia may experience other comorbid conditions such as diabetes, hypertension, renal disease, and cancer and who added that; these challenges may complicate the management of adult patients further are associated with increased bleeding symptoms and clotting factor consumption.

More than forty percent of the hemophilic patients had hepatitis C in comparison with the results of the previous studies done by Tawfik et al. [18] who found positive HCV in more than five percent of studied hemophilic patients. Also Tonbary et al. [22] in their study reported that; hepatitis C infection and arthropathy represented the complications in patients with hemophilia and they added that; unfournitly, those patients are potential risks underlying the use of blood products. Although, 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 [24].

Based on literature review, studied patients suggestions and from the researcher point of view, recombinant clotting factor concentrates are considered the gold-standard therapy and are the recommended treatment of choice for people with hemophilia in Egypt. If resources are limited, virally inactivated plasma-derived concentrates can be used. Due to the high prevalence of HCV in Egypt, cryoprecipitate, fresh frozen plasma and solvent and detergent filtration cryoprecipitate should only be used in emergency situations when no alternatives are available.

Regarding common sites of bleeding, the finding of this study revealed that; more than thirty five percent and thirty percent of the hemophiliac patients were had bleeding in knees joints and epistaxis respectively. These finding are congruence with study carried by Knobe & Berntorp, [25] who reported that; bleeding most commonly occurs in the knees, elbows, and ankles, and is often evident from early childhood. The most common physical complications detected in the current study were deformity in the shapes and functions of knee joints which represented in more than thirty five percent. This results were in concordant with that of Tonbary et al. [22] who reported that; hemarthrosis was the most common complication among hemophilic patients, also Tawfik et al. [18] in their study reported that; the most common complications were hemarthrosis in more than twenty five patients, muscle hematoma in more than fifteen percent.

Concerning psychological, social and financial problems caused by the disease, the finding of this study revealed that; the high incidence of work absenteeism and insufficient income, unavailability of clotting factors medications, inability to do social activities and play the role, feeling of loneliness and insecurity, and unable to achieve educational requirements. These findings were in agreement with study done by Treil [23] who reported that; numerous challenges confront adult hemophilic patients are deterioration of joints, physical disability, emotional turmoil, and social issues. Moreover, treatment regimens often used in the treatment of patients with hemophilia impose significant scheduling, economic, and emotional demands on patients and their families or primary caregivers. Patients have higher incidences of mobility-related problems, hospitalizations, school and work absenteeism, and difficulty maintaining a job, along with higher treatment costs. In the same line [26] reported that; although the complications of hemophilia result in numerous psychosocial outcomes, to the best of our knowledge, no previous study has evaluated these complications and their prevention methods.

■ Section II

The current study showed that, forty percent of the studied patients the main source of their information was from other patients while less than ten percent of them received information from heath team members. In comparison with Cutilli et al. [27] who reported that; the most common and trusted source of information for patients is healthcare professionals, and they added that; patients use other sources of health information (e.g., TV, internet, and family/friends/co-workers) to supplement information provided by healthcare professionals.

In the current study, ninety percent of the studied patients stated that; medical team didn't receive patients when they were admitted to the hospital and they didn't find the medical team when they needed them. Moreover, all studied patients didn't receive hospital orientation, engaged in their treatment plan, and perform any kind of hobbies/leisure activities while

they are in the hospital. These results were in concordant with the results of the study done by Balogun et al. [28] they revealed lack of adequate knowledge about hemophilia and the management of this rare bleeding disorder among health care providers. Also Zhao et al. [15] pointed out that; hemophilia is a rare disease with complicated diagnosis and management. Patients are helpless because the other personnel are unprofessional.

The study results showed that; all patients did not practice any type of exercises or any type of physiotherapy (therapeutic exercises) because there was not one to help them to practice exercise, and unawareness as well as fear of bleeding was the main reasons of non-practicing therapeutic exercises. The finding agrees with El Dakhakhny et al. [29] who carried study adolescents patients with hemophilia and reported that; all the studied patients didn't practice therapeutic exercises. Also they added that; physiotherapy, physical activity and sport are basic elements to improve the quality of life and the physical condition.

Regarding patients' satisfaction more than ninety five percent of them didn't satisfied with the medical services provided to them, in this line [30] reported that; patient satisfaction in hemophilia, a fundamental component of medical care and an indicator of the quality of medical care provided. Moreover, the value of patient satisfaction is particularly apparent in the setting of chronic disease where medical care utilization is high, compliance with therapy is critical and the patient-provider relationship is often long-term.

Regarding to patients' suggestions to improve medical services forty percent of them suggested that; raising health team members and community members' awareness about the disease. These results were in concordant with that of Balogun et al. [28] and Nilson and Schachter [31] they reported that; the knowledge of the clinical features and management of hemophilia needs to be improved. Lack of adequate knowledge about hemophilia and the management of this rare bleeding disorder among health care providers is of a serious public health concern and likely to increase morbidity and mortality.

On the other hand, limited therapeutic resources in developing countries and ineffectiveness of the existing treatments (increased inhibitor antibodies in some patients) necessitate development of new efficient methods for reducing the disease complications. In the same text [32] in their study reported that; the need for a more integrated, multidisciplinary approach to care for individuals with bleeding disorders has been highlighted in recent years. Evidence-based education adapted to nurses' needs is essential for a successful evolution.

Also Valizadeh et al. [26] pointed out that; educating health team members in preventing complications of hemophilia will not only have remarkable economic benefits, but will also inhibit the unexpected complications due to the use of therapeutic products and enhance the patients' quality of life. Hemophilia associations should be recommended for educational programs for patients and caregivers, as well as publishing simple books or brochures in each local language to improve the knowledge [33].

More than third of studied patients suggested establishing specialized hospitals to provide comprehensive care for patients with hemophilia. In fact, health insurance opens the first specialized center in Egypt for the treatment and care of hemophilia patients in 18-9-2018. Hemophilia represents a high-cost, low-volume disease hence, in developing countries where ninety percent of hemophilia patients of the world live; it puts the government of the day in a conundrum, i.e. the limited resources of that country earmarked for health need to be distributed amongst management and prevention of various diseases which optimally helps the population of the country. Hence, there is a need for developing research protocols suitable for that country in an evidence-based manner [34].

Conclusion

■ Highlights

- Patients with hemophilia have physical, psychological and social needs
- Patients should adhere to comprehensive instructions from health team members
- Application of clinical pathway may provide comprehensive health care for these patients
- Availability of coagulation factors as a treatment should be recommended

- Establish specialized hospitals able to provide care for patients with hemophilia

This therapeutic clinical pathway is designed to provide comprehensive care based on evidence based practice to improve quality of care, decrease cost, support effective discharge plan, and decrease mortality and morbidity rate for the patients with different types of hemophilia.

■ Responsible person (leader)

Hematology nurse is the responsible one to coordinate and follow application of clinical pathway.

■ Inclusion criteria

An adult conscious male patient, age from 18-60 years, with all types of hemophilia.

Instructions to use clinical pathway for the patients with all types of hemophilia **(FIGURE 1)**.

- This pathway is used for patients with all types of hemophilia with inclusion criteria.
- Clinical pathway diagram is color coded; each block indicates specific part in the pathway.
- Expected outcomes are match with activity through color cod in a small circle before each statement.
- Responsible hematology health team is match with activity through assigning numbers presence after each statement.
- Time line for this pathway is from patient's hospital admission until discharge including emergency time.

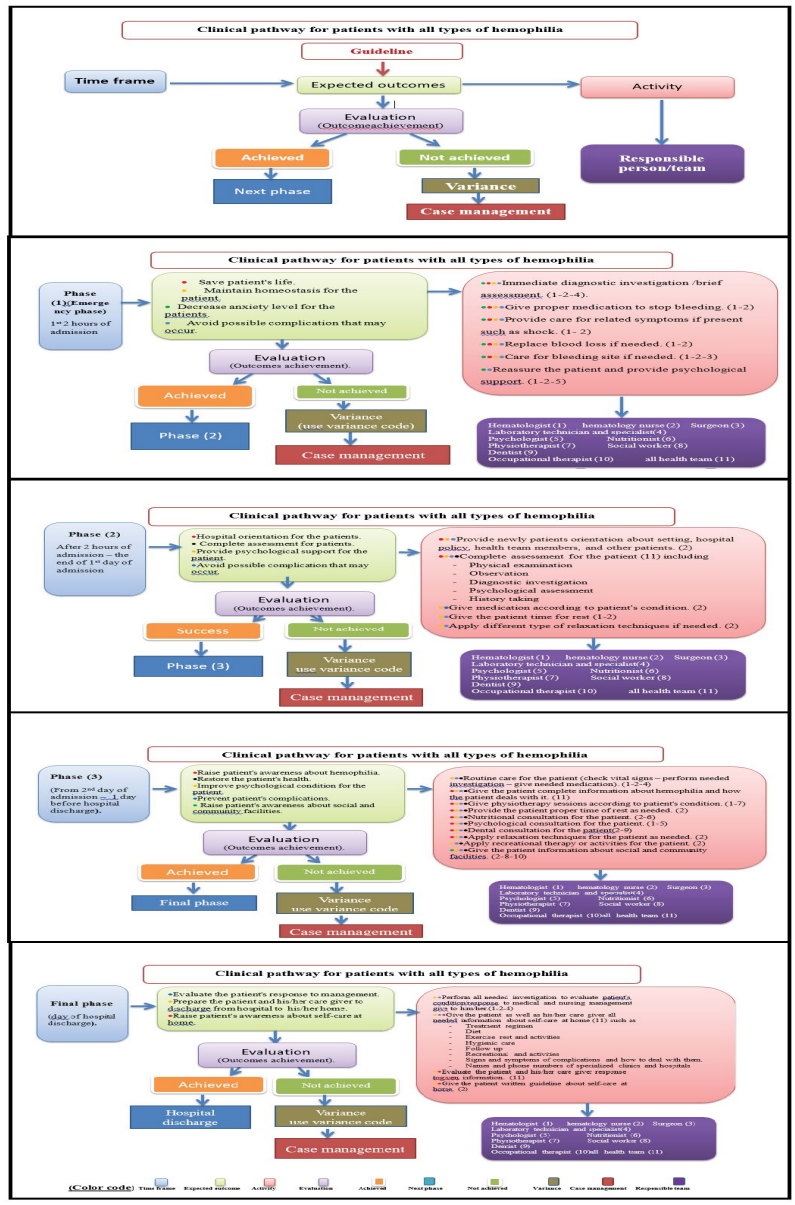

FIGURE 1. Clinical pathway for patients with all type of hemophilia.

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