

Impact and disease burden in moderate and severe hemophilia from patient and nursing perspective. The NURSES-WHO-CARE study

Impacto y carga de la enfermedad en hemofilia moderada y grave desde la perspectiva del paciente y de enfermería. Estudio NURSES-WHO-CARE

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Abstract

Introduction: Pain, bleeding frequency, and functional status are major concerns for patients with hemophilia and caregivers.

Objective: The study aimed to evaluate the disease burden in patients, the knowledge of patients on their disease and treatment, and the role of the specialized nurses in the care of these patients in Spain. **Material and method:** This was a non-interventional, cross-sectional, multicenter study. A total of 103 patients with moderate or severe hemophilia A (89 adults and 14 children), 14 caregivers, and 16 nurses from Spain (NURSES-WHO-CARE study) participated in the study. **Results:** About 32.6% of adult patients stated to rarely think about hemophilia. Most of the patients (99%) stated to know its signs and symptoms. Regarding nurses, all of them pointed out to participate in the education of patients and/or caregivers in terms of disease, treatment, and adherence, among others. **Conclusion:** Hemophilia has an impact on patient's and caregiver's daily lives despite care improvements and new treatments. Patient's knowledge on their disease and treatment remains an important aspect influencing their care. The specialized nurse is a central figure in this education and comprehensive care, especially in moderate and severe cases.

Keywords: Hemophilia. Burden. Knowledge. Nursing. Care. CATCH.

Resumen

Introducción: El dolor, la frecuencia de hemorragias y el estado funcional son preocupaciones importantes para los pacientes con hemofilia y sus cuidadores. **Objetivo:** Evaluar la carga de la enfermedad en pacientes y cuidadores, el conocimiento de los pacientes sobre su enfermedad y tratamiento, y el papel del profesional de enfermería especializado en el cuidado de estos pacientes en España. **Material y método:** Estudio no intervencionista, transversal y multicéntrico. Participaron 103 pacientes con hemofilia A moderada/grave (89 adultos y 14 niños), 14 cuidadores y 16 enfermeras (Estudio NURSES-WHO-CARE). **Resultados:** El 32,6% de los pacientes adultos afirmó pensar raramente en la hemofilia. La mayoría de pacientes (99%) afirmó conocer sus signos y síntomas. Respecto al profesional de enfermería, todos señalaron participar en la educación de los pacientes y/o cui-

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dadores en términos de enfermedad, tratamiento, adherencia, entre otros. **Conclusión:** La hemofilia tiene un impacto en la vida diaria del paciente y del cuidador pese a las mejoras en el cuidado y nuevos tratamientos. El conocimiento que tiene el paciente sobre su enfermedad y tratamiento sigue siendo un aspecto importante que influye en su cuidado. El profesional de enfermería es una figura central en esta educación y en la atención integral del paciente, especialmente en casos moderados y graves.

Palabras clave: Hemofilia. Carga. Conocimiento. Enfermería. Cuidado. CATCH.

Introduction

Hemophilia is a rare condition characterized by the deficiency of the coagulation factor VIII (hemophilia A) or factor IX (hemophilia B)¹. Hemophilia A is the most frequent type of disease, accounting for 80-85% of cases². Its severity is based on plasma levels of factor VIII, i.e. mild (if > 5% of normal), moderate (1-5%), and severe (< 1%)³. Patients with mild hemophilia A usually experience bleeding episodes only after serious surgical procedures, injury, or trauma; whereas moderate cases tend to suffer them after any injury². Severe cases frequently present spontaneous bleeding episodes, especially in joints and muscles. In addition to the pain and limitation during bleeding episodes, complications may lead to chronic pain, severe joint damage, and disability⁴. Despite significant advances in treatments, the disease continues causing a major impact on patients' daily activities and quality of life (QoL)⁴. The identification and prioritization of patient-relevant health outcomes (PROs) have thus become necessary for optimizing and individualizing the care of patients with hemophilia⁵. Previous studies have also revealed that patients with severe and moderate hemophilia A show a lack of knowledge on their disease and treatments^{6,7}. Moreover, treatment adherence is usually lower in patients with a poor degree of this knowledge, and thus, their risk for bleeding episodes and complications is higher than those with an adequate knowledge⁸. The optimal management of hemophilia, especially for severe cases, requires comprehensive care provided by a multidisciplinary team of health-care professionals⁹. Among them, specialized nurses play a key and coordinating role in the care of these patients, such as taking part in treatment/supplies, monitoring of complications, training for home treatment, and many other aspects^{10,11}. Specialized nurses also have an essential role in the education of patients and families and, in turn, encouraging adherence to prophylactic regimens¹². To the best of our knowledge, scarce reports have described the role of the specialized nurse in the care of patients with hemophilia A. In fact, none of them^{10,11} have been addressed in Spain. In addition, none of the previous studies have evaluated at the

same time three important aspects associated with hemophilia A and the patient's care: the disease burden, the patient's knowledge, and the role of specialized nursing care. Therefore, the objective of the study was to evaluate the disease burden (PRO) in patients with moderate and severe hemophilia A and caregivers as well as to determine the health literacy level of our population and their perceptions about the role of specialized nurses in hemophilia.

Methods

Study design and participants

The NURSES-WHO-CARE was a non-interventional, cross-sectional, multicenter study that involved patients with moderate and severe hemophilia A, their caregivers (i.e. parents/individuals who care of the children with hemophilia), and nurses who take care of the patients in Spain. The inclusion criteria of patients were age ≥ 12 years and with the diagnosis of moderate or severe hemophilia A, regardless of the development of inhibitors against factor VIII. Patients not able to understand or complete the questionnaires (according to the nurse's criteria) were considered as non-eligible. There were no inclusion criteria for the nurses. Patients were consecutively recruited at each hospital to reduce selection biases. The study consisted of a single visit which coincided with one of the patient's routine follow-ups. The study was carried out in accordance with the Declaration of Helsinki and National regulations and was approved by the Ethics Committee of each one of the 16 participating centers. All patients gave their written informed consent to participate in the study.

Study assessments

The primary endpoint was to examine the impact of hemophilia (PRO) on patients and caregivers using the hemophilia-specific, self-reported Comprehensive Assessment Tool of Challenges in Hemophilia (CATCH) questionnaire¹³. It consists of seven domains: preoccupation on the disease; the impact of the

disease on daily activities, social activities, and recreational activities; the impact of the disease on work/college/school; the impact of the disease treatment; and pain. Items are scored qualitatively using ordinal scales (4-5 points for adults/caregivers, and 3-4 for children), and qualitatively using 11-point numeric rating scales. The CATCH questionnaire also provides scores for domains and items, ranging from 0 to 100. The calculation of CATCH scores is fully explained in the supplementary material (Supplementary Tables 1-4). The CATCH questionnaire has been validated in patients with hemophilia A and B and their caregivers¹³. Secondary endpoints included the patient's knowledge of their disease and treatments and the role of nurses in the hemophilia's patient care. These secondary analyses were assessed using two adapted questionnaires, that were specifically designed by the main investigators (based on their experience and previous literature)^{6,9,10,14}. The English translations of the adapted questionnaires are shown in the supplementary material. Nurses participating in the study completed the adapted questionnaire on their role in hemophilia patient care electronically and individually to avoid any influence on their responses. Similarly, as self-administered questionnaires, nurses were asked to allow patients to complete the CATCH and the one on their disease and treatment knowledge individually and without the presence of the nurse to avoid any interference.

Statistical analysis

Continuous variables are shown as mean, SD, median, and interquartile range (IQR), as appropriate; whereas categorical ones as absolute and relative frequencies. Sample size determination is shown in the Supplementary material. Missing data were not considered in the analyses. All analyses were performed using the Statistical Package for the Social Sciences (SPSS) version 22.0 (SPSS Inc., Chicago, IL, USA).

Results

Participants

From September 2021 to April 2022, a total of 103 patients were enrolled in the study. None of them were excluded. Of the patients, 89 and 14 were adults and children, respectively. Moreover, 14 caregivers and 16 nurses also participated in the study. Patients were predominantly male, with a mean age of

33.9 years (SD: 14.2; **Table 1**). Of them, 83.5% and 16.5% had severe or moderate hemophilia A, respectively. Clinical characteristics of patients regarding the type of hemophilia are reported in the Supplementary Table 5. Most of the patients (93.2%) were on prophylactic treatment.

CATCH questionnaire

Adult patients rated the limitations of the disease on daily activities with a mean of 4.8 (SD: 2.4, scale 1-10; values ranging from 1, "not restricted at all", to 10, "extremely restricted"). Moreover, 61.8%, 49.4%, and 43.2% of them pointed out low risk for bleeding in daily, social, and recreational activities (Supplementary Table 6). In addition, 64.3%, 78.6%, and 28.6% of the children indicated no perceived risk for bleeding in such activities. Regarding the perception of pain, 14.6% of the adult patients suggested to have experienced a bleed in the past 7 days (Supplementary Table 7). For children, the mean rate of worst pain experienced over the past 7 days was 2.5 (SD: 0.6). All mean CATCH scores were numerically higher in adult patients than children, excepting recreational risk perception (31.4 versus 33.8, respectively; **Fig. 1**). Regarding preoccupation on hemophilia, 32.6% of the adult patients stated that they rarely think on hemophilia, 50% of the children indicated to have thought on hemophilia the past week, and 35.7% of the caregivers pointed out to always think about their child's hemophilia (**Table 2**).

Patient's knowledge on their disease and treatment

According to the patients, 81.6% and 16.5% had severe or moderate hemophilia A, respectively (**Table 3**). The majority of them (99.0%) stated to know the signs and symptoms associated to hemophilia, especially thanks to health professionals with whom they interact (69.9%) or their own experience (52.4%). Of patients, 57.3% pointed out to know the risks associated with hemophilia mainly thanks to hematologists (100.0%), nurses (88.3%), and pharmacists (62.1%). All patients indicated to know the importance of correctly following the treatment and indications for hemophilia indicated by their physician. Most of the patients (96.1%) suggested to be trained and with adequate knowledge to continue their treatment safely and effectively from home, and 94.9% (94 out of 99 patients) indicated that this was a result of the communication

Table 1. Sociodemographic and clinical characteristics of patients

Characteristics	Patients (n = 103)
Sex, male, n (%)	102 (99.0)
Age, mean (SD), years	34.0 (21.0-43.0)
Most frequent comorbidities/relevant concomitant disease*	
Hepatitis C virus infection	28 (27.2)
Arthropathy	24 (23.3)
HIV infection	22 (21.4)
Arterial hypertension	8 (7.8)
Time of hemophilia diagnosis, n (%) [†]	
Within the first 3 months of life	21 (20.4)
Between the first 3 and 9 months of life	29 (28.2)
Beyond the 9 months of life	45 (43.7)
Bleeding episodes treated with factor VIII in past 12 months, n (%)	50 (48.5)
Number of bleeding episodes treated with factor VIII in past 12 months, median (IQR) [†]	2.0 (1.0-4.0)
Type of current treatment for hemophilia, n (%)	
Prophylactic	96 (93.2)
On-demand	7 (6.8)
Number of visits to the specialist that were scheduled per year for the management of hemophilia A, median (IQR) [‡]	3.0 (2.0-6.0)
Number of visits to the specialist carried out in the past year for the management of hemophilia A, median (IQR)	6.0 (3.0-10.0)

*Multiple choice.

Missing data: n = 8[†], n = 6[‡].

SD: standard deviation; IQR: interquartile range; HIV: human immunodeficiency virus.

and relationship with nurses. Regarding the experience of patients with the specialized nurses, all of the patients considered necessary the role of the specialist nurse within the care team. Patients rated the importance of the role of the specialist nurse within the care team as a median of 10.0 (IQR: 9.0–10.0, with values ranging from 0 “nothing necessary” to 10 “extremely necessary”).

Role of the specialized nurses in the hemophilia's patient care

Of nurses who completed the questionnaire (n = 16), 43.8% had 3-5 years of experience with coagulopathies (Table 4). Most of them (93.8%) indicated to work in a center with regular consultation for coagulopathies, especially daily or 4 times a week (80%), and as a multidisciplinary team, mainly with pharmacy (87.5%), physiotherapy (87.5%), hematology (87.5%), rehabilitation (75%), and traumatology services (75%). All of the nurses pointed out to participate in the education of patients and/or caregivers in terms of disease, treatment, and adherence, among others. Further characteristics of nurses and their role in hemophilia patient care are shown in Supplementary Table 8. Of nurses,

50.0% stated to have interactions regularly with patients and/or caregivers, by exchanging experiences related to their health and trying to follow their condition and evolution, even if they are at home. Moreover, 87.5% indicated to participate in the disease process and facilitate the teaching that allows them to continue with home treatment.

Discussion

This study aimed to show three aspects associated with hemophilia A patient's care, that is, the disease burden on the patient and caregiver's daily lives, the knowledge of patients on their disease and treatment (having potential consequences on the patient's care), and, finally, the role of the specialized nurses to cope with patient's education and further competences. Pain, bleeding frequency, and functional status are major concerns for patients with hemophilia and caregivers and affect their lifestyle and QoL¹⁵. The present study represents the first published one in determining the impact of hemophilia and its treatment on patients with hemophilia and their families (as a PRO) in Spain in routine clinical practice. To date, only two previous reports (not published) have used the novel CATCH questionnaire,

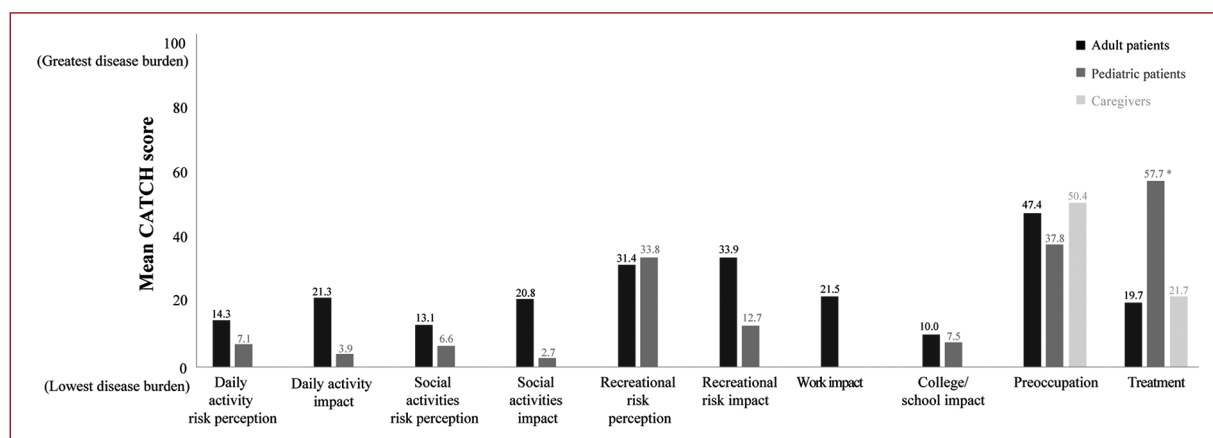


Figure 1. Disease burden (CATCH scores) in patients and caregivers. *Regarding the treatment CATCH score in children, higher values represent a lower perceived burden of the hemophilia treatment. CATCH: Comprehensive Assessment Tool of Challenges in Hemophilia questionnaire.

mostly to describe its comprehensiveness and reliability^{13,16}. Only a recent phase III study with emicizumab showed an improvement in the treatment burden in patients with hemophilia A using the CATCH questionnaire¹⁷. Our results highlight the disease burden that is present in adult and pediatric patients, as well as caregivers. According to patients, its impact is evident in the simplest daily life activities, for example standing for a long time, walking up one flight of stairs, or playing rough with kids in the case of adult patients, or brushing the teeth, putting on socks and shoes, or when walking down one flight of stairs in the case of kids. In addition, according to adult patients, hemophilia has not a notable impact on work or college, although it is more evident when doing physical tasks. Despite the perceived risk in daily activities, almost one in two patients tries to live as normal, and only one in five often thinks about the disease. Furthermore, the preoccupation of caregivers with the child's disease is frequent. When comparing populations, adult patients showed higher preoccupation with the disease than children; however, caregivers showed a preoccupation even greater than patients. Regarding school, children stated even less impact of hemophilia on it, if compared with adults at work or college. All these results are in agreement with previous studies and show how the improvements in treatment influence them¹⁵. The patient's knowledge on their disease and treatment is an important factor influencing the treatment adherence and, in turn, the patient's care⁶. Several studies have found a positive association between knowledge about the disease, treatment adherence, and achieving better outcomes (such as in QoL and management

bleeding episodes)^{6,18}. Besides this, previous studies have revealed that patients with severe and moderate hemophilia have a lack of knowledge in specific areas^{6,7}. In our study, patients had an adequate level of knowledge, as practically all of them (99%) indicated to know the signs and symptoms associated with hemophilia, and the type of hemophilia (98.1%). It is interesting to note that two of our patients (1.9%) indicated to have a mild disease, however, they actually were diagnosed with moderate (one case) and severe (the other one) disease. This observation highlights the need to reinforce the education of patients on their disease, risks of complications, benefits of treatments, and the importance of self-care. The types of treatments that indicated the patients were also in line with the information provided by the investigators (nurses). According to patients, the knowledge on the disease and treatment was mainly obtained from information provided by healthcare professionals (69.9%) or even their own experience (after many bleeding episodes, 52.4%). All patients indicated to know the importance of correctly following the treatment and indications from the physician. Most of the patients pointed out the figure of the nurses for educating them about the impact and implications of hemophilia. Accordingly, guidelines of the World Federation of Hemophilia recommend that patients with hemophilia are managed at a specialized comprehensive care center through a multidisciplinary, specialized care team⁹. Nurses specialized in hemophilia are indeed pivotal in this care¹⁹. With the exception of limited reports from UK^{10,11,19}, the evidence on the role and competencies of the specialized nurses in hemophilia is practically lacking.

Table 2. Impact of hemophilia in preoccupation, work/college/school activities, and hemophilia treatment on patients and caregivers

	Never	Rarely	Sometimes	Often	Always
Preoccupation (CATCH question: "Overall, in a typical day, how often do you think about hemophilia?", n (%))*					
Adults (n = 89)	15 (16.9)	29 (32.6)	25 (28.1)	15 (16.9)	5 (5.6)
Children (n = 14)	4 (28.6)	-	7 (50.0)	3 (21.4)	0 (0.0)
Caregivers (n = 14)	0 (0.0)	2 (14.3)	3 (21.4)	4 (28.6)	5 (35.7)
	Never	Rarely	Sometimes	Most of the time	-
Work/college/school activities (CATCH question: "How often does hemophilia impact your ability to work/go to school and/or do schoolwork?"), n (%)*					
Adults: Work (n = 89)	14 (21.9)	30 (46.9)	19 (29.7)	1 (1.6)	-
Adults: College/school (n = 89)	10 (52.6)	9 (47.4)	0 (0.0)	0 (0.0)	-
Children: School (n = 14)	8 (57.1)	-	6 (42.9)	0 (0.0) [†]	[†]
	Not at all	A little	Moderately	Quite a bit	Extremely
Hemophilia treatment					
Adults (n = 89): CATCH question: "Overall, how much are you bothered by your hemophilia treatment?", n (%)*					
	33 (37.1)	30 (33.7)	17 (19.1)	8 (9.0)	1 (1.1)
Children (n = 14): CATCH question: "Overall, how much do you like or dislike your hemophilia treatment", n (%)*					
	Dislike a lot	Dislike a little	Like a little	Like a lot	-
	1 (7.1)	2 (14.3)	5 (35.7)	6 (42.9)	-
Caregivers (n = 14): CATCH question: "Overall, how much of a problem for you is your child's hemophilia treatment?", n (%)*					
	Not at all	A little	Moderately	Quite a bit	Extremely
	9 (64.3)	3 (21.4)	1 (7.1)	1 (7.1)	0 (0.0)

*In quotation marks and italics are shown the questions for each item as written in the CATCH questionnaire.

[†]For children, instead of most of the time, answers were "often" and "always". Both responses were 0.0%.

In our study, results pictured nurses as healthcare professionals with experience on coagulopathies, who undertake and promote health education, collaborate with other healthcare centers in research and exchange of best practices, offer laboratory services with 24-h coverage, and provide regular follow-up and treatment at home, if necessary, among other qualities. They usually participate in the disease process, encourage the patient on treatment adherence, and positively influence the perception of the patient's disease.

The main limitation of the study was the relatively low number and, thus, the size heterogeneity among adult, children, and caregiver populations (89:14:14). In addition, no information on the caregiver's knowledge of the disease was collected. Regarding the patient's

knowledge and the role of the specialized nurses, data were provided from limited questionnaires, without inferring any correlation. For instance, including items able to correlate the level of the patient's knowledge with the patient/caregiver's disease burden or the education role of specialized nurses with the patient's knowledge would have greatly strengthened the conclusions. Another limitation derives from the fact that the two adapted questionnaires have not been yet validated in patients with moderate or severe hemophilia. Nevertheless, they were created and used because, after a literature search, none of the available validated questionnaires was able to fully meet the objectives of the present study. Besides these limitations, this study provides an up-to-date picture of the important impact of hemophilia on patient's

Table 3. Knowledge of patients on their disease, treatment, and healthcare professionals

Variables	Patients (n = 103)
Disease*	
Type of hemophilia, n (%)	
Mild (Factor VIII between 5 and 30%)	2 (1.9)
Moderate (Factor VIII between 1 and 5%)	17 (16.5)
Severe (Factor VIII < 1%)	84 (81.6)
Having knowledge of signs and symptoms associated with hemophilia, n (%)	102 (99.0)
How achieving the knowledge on signs and symptoms, n (%)	
“Thanks to the health professionals with whom I interact”	72 (69.9)
“After many episodes/bleeds, I have learned to recognize them”	54 (52.4)
“I have always had an interest and I usually look for current information on the disease”	36 (35.0)
“I maintain contact with patient associations and attend talks or congresses about my disease”	30 (29.1)
Having knowledge of the risks associated with hemophilia, n (%)	
“Yes, I try to minimize them as possible”	36 (35.0)
“Yes, although I try to lead a life as normal as possible, as if I did not have the disease”	59 (57.3)
“Not all of them (risks), for this reason, I prefer avoiding any situation that could compromise my health”	7 (6.8)
“No knowledge, I carry out all types of activities and I have never had any problem”	1 (1.0)
Having the training and knowledge to follow the treatment safely and effectively from home, n (%)	99 (96.1)
Achieving the training and knowledge to follow the treatment safely and effectively from home is the result of communication and relationship with nurses, n (%) [‡]	94 (94.9)
Family, friends, and/or co-workers	
Family, friends, and/or co-workers having knowledge on their disease, n (%)	99 (96.1)
Family, friends, and/or co-workers having knowledge adequate knowledge for dealing with a bleeding episode, n (%) [‡]	78 (78.8)
Treatment	
Type of current treatment, n (%) [‡]	
On-demand	7 (6.8)
Prophylactic	95 (92.2)
Duration of the treatment, n (%) [‡]	
< 6 months	11 (10.7)
Between 6 months and 1 year	3 (2.9)
Between 1 and 3 years	16 (15.5)
Between 3 and 5 years	10 (9.7)
More than 5 years	62 (60.2)
Healthcare professionals*	
Most frequent healthcare professionals with whom to interact for their disease, n (%)	
Hematologists	103 (100.0)
Nurses	91 (88.3)
Pharmacists	64 (62.1)
Rehabilitators	41 (39.8)
Traumatologists	38 (36.9)
Physiotherapists	35 (34.0)
Dentists	34 (33.0)
Characteristics of nurses, n (%) [§]	
“They meet and educate you about the impact and implications of hemophilia”	72 (70.0)
“You feel that they listen to you, you can talk openly about what difficulties you have in reference to the treatment or the disease and collaborate in the search for solutions”	69 (67.0)
“They promote adherence to treatment and know its degree of compliance and its evolution, participate in the disease process, and facilitate teaching that allows you to continue with home treatment”	67 (65.0)
“They positively influence their perception of the disease and motivate the achievement of objectives”	59 (57.0)
Possibility of interacting with nurses, n (%)	
“Exclusively when I go to the hospital and require nursing care”	39 (37.9)
“Regularly. We exchange experiences related to my health and try to follow my condition and evolution, even though I am at home”	38 (36.9)
“Occasionally, if I experience a worsening of my health condition, as well as when I go to the hospital and require care”	26 (25.2)
Importance of the figure of the specialist nurse within the healthcare team, median (IQR)**	10.0 (9.0-10.0)

*In quotation marks and italics are shown the answers as written in the CATCH questionnaire.

Missing data:

n = 4[†], n = 1[‡].[§]Multiple choice.[‡]Calculated over the 99 participants who responded “Yes” at “Having the training and knowledge to follow the treatment safely and effectively from home”.^{**}Values ranging from 0 “nothing necessary” to 10 “extremely necessary”.

Table 4. Characteristics of nurses and their role in hemophilia's patient care

Characteristics	Nurses (n = 16)
Years of experience with coagulopathies, n (%)	
More than 15 years	2 (12.5)
Between 10 and 15 years	1 (6.2)
Between 5 and 10 years	3 (18.8)
Between 3 and 5 years	7 (43.8)
Between 1 and 2 years	3 (18.8)
2-3 times a week	2 (13.3)
Once a week	1 (6.7)
Nurses who work in a center with specific protocols for the care of people with hemophilia	13 (81.2)
Nurses who work in a center with a multidisciplinary team treating coagulopathies, n (%)	15 (93.8)
Most frequent specialties included in the multidisciplinary team, n (%)*	
Pharmacy	14 (87.5)
Physiotherapy	14 (87.5)
Hematology	14 (87.5)
Rehabilitation	12 (75.0)
Traumatology	12 (75.0)
Number of patients with coagulopathies who regularly visit the coagulopathy consultations, n (%)	
More than 500	5 (31.2)
Between 200 and 500	4 (25.0)
Between 50 and 200	5 (31.2)
< 50	2 (12.5)
Description of the nursing role, n (%)†	
"I understand the principles and objectives of the procedures, I deal with complex but predictable situations. I recognize real and potential problems and prioritize effectively"	5 (31.2)
"I interact in complex and demanding situations. I have practical skills appropriate and specific to the needs of the patient and I apply intuitive decision-making"	5 (31.2)
"I start innovative practices. I demonstrate excellence and act as a role model/guide for my peers. I can deal with complexity and critically assess the use of theory/research in practice"	3 (18.8)
"I follow the procedures of the policies and principles, focusing on only one aspect of care at a time"	2 (12.5)
"I recognize and prioritize the need for actions. I make limited decisions when I am aware/experienced/safe of the situation"	1 (6.2)
Interaction with patients and/or their caregivers, n (%)‡	
"Exclusively when they go to the hospital and require nursing care"	4 (25.0)
"Occasionally, if there is a worsening of their health condition, in addition to when they go to the hospital and require nursing care"	4 (25.0)
"Regularly. We exchange experiences related to their health and I try to follow their condition and evolution, even if they are at home"	8 (50.0)
Nurses who promote or participate in the learning of patients and/or caregivers, n (%)	16 (100.0)
Ways to promote and participate in this learning, n (%)*†	
"I participate in the disease process and facilitate the teaching that allows them to continue with home treatment"	14 (87.5)
"I encourage adherence to treatment and keep abreast of its degree of compliance and evolution"	11 (68.8)
"I am able to positively influence their perception of the disease and motivate the achievement of objectives"	8 (50.0)
"I know and disclose the social/economic impact and implications of hemophilia on patients and their families"	6 (37.5)
Others	3 (18.8)

*Multiple choice.

†In quotation marks and italic are shown the answers as written in the adapted questionnaire.

and caregiver's daily life, the patient's knowledge of their disease and treatment, and highlights the role of the specialized nurses in the care of these patients.

Conclusion

This study shows that hemophilia has an impact on patient's and caregiver's daily lives despite improvements

and new treatments. Patient's knowledge on their disease and treatment remains an important aspect influencing their care. Specialized nurses are a central figure in this education and comprehensive care, especially in moderate and severe cases. Although our study represents a first step on the use of the CATCH questionnaire, further studies involving larger cohorts of patients and caregivers are required to confirm the present results.

Supplementary data

Supplementary data are available at DOI: 10.24875/SANGREE.24000009. These data are provided by the corresponding author and published online for the benefit of the reader. The contents of supplementary data are the sole responsibility of the authors.

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Conflicts of interest

S. García-Barcenilla has participated as a speaker in advisory boards and sponsored symposia with Roche, NovoNordisk, CSL Behring, Takeda, Sobi, Biomarin, Novartis, Bayer, and Pfizer. E. Álvarez-Martínez has participated as a speaker in advisory boards and sponsored symposia with Bayer, CSL Behring, Pfizer, Octapharma, Roche, Sobi, and Takeda. F.J. López-Jaime has received research funding from Roche and Sobi, and has participated as a speaker in advisory boards and sponsored symposia with Amgen, Bayer, CSL Behring, Novartis, Novo Nordisk, Pfizer, Roche, Sobi, and Takeda. M. Rambla-Pérez and Y. Echarte-Buil have received support for attending meetings and/or travel from Roche and Sobi, and consulting fees from Roche. P. Bosch has received payment/honoraria from Roche, Pfizer, and Bayer. P. González-Álvarez has received consulting fees and payment/honoraria from Roche. C. Álvarez and I. Guerra are employees of Roche Farma Spain. A.T-O has received consulting fees from Roche and Biomarin, and payment/honoraria from Roche.

Ethical considerations

Protection of humans and animals. The authors declare that the procedures followed complied with the ethical standards of the responsible human experimentation committee and adhered to the World Medical Association and the Declaration of Helsinki. The procedures were approved by the institutional Ethics Committee.

Confidentiality, informed consent, and ethical approval. The authors have followed their institution's confidentiality protocols, obtained informed consent from patients, and received approval from the Ethics Committee. The SAGER guidelines were followed according to the nature of the study.

Declaration on the use of artificial intelligence. The authors declare that no generative artificial intelligence was used in the writing of this manuscript.

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