



## NURSES' KNOWLEDGE OF HEMOPHILIA CLINICS OF ON SYSTEMATIZATION NURSING CARE

### CONHECIMENTO DAS ENFERMEIRAS DE AMBULATÓRIOS DE HEMOFILIA SOBRE A SISTEMATIZAÇÃO DA ASSISTÊNCIA DE ENFERMAGEM

### CONOCIMIENTO DE LAS ENFERMERAS DE CLINICAS DE HEMOFILIA SOBRE LA SISTEMATIZACIÓN DE LA ASISTENCIA DE ENFERMERÍA

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#### ABSTRACT

**Objective:** to assess the knowledge of nurses on the Systematization of Nursing Care. **Method:** a descriptive study with a qualitative approach, conducted with eight nurses of hemophilia clinics of Ceará. For the production of data, a questionnaire was used. The data were processed by Microsoft Excel 2010 program analyzed by thematic categorization. **Results:** it was found that 8 (100%) of survey participants conceptualized the SAE as “a process or work tool, designed to help and guide the delivery of care.” **Conclusion:** it was possible to identify the desire of these professionals on the need for training and standardization of SAE in care practice. The implementation was considered to be a relevant action, given the benefits that can provide patients, professionals, and the institution. **Descriptors:** Hemophilia A; Nursing Care; Nursing Processes.

#### RESUMO

**Objetivo:** avaliar o conhecimento das enfermeiras sobre a Sistematização da Assistência de Enfermagem. **Método:** estudo descritivo, com abordagem qualitativa, realizado com oito enfermeiras dos ambulatórios de hemofilia do Ceará. Para a produção de dados foi utilizado um questionário. Os dados foram processados pelo Programa Microsoft Excel 2010 e analisados por categorização temática. **Resultados:** constatou-se que 8 (100%) das participantes da pesquisa conceituaram a SAE como sendo um “processo ou ferramenta de trabalho, desenvolvido para auxiliar e nortear a prestação da assistência”. **Conclusão:** foi possível identificar o anseio destas profissionais quanto à necessidade de capacitação e padronização da SAE na prática assistencial. A implementação foi considerada como sendo uma ação relevante, tendo em vista os benefícios que poderá proporcionar aos pacientes, aos profissionais e à instituição. **Descritores:** Hemofilia A; Assistência de Enfermagem; Processos de Enfermagem.

#### RESUMEN

**Objetivo:** evaluar el conocimiento de las enfermeras sobre la Sistematización de la Asistencia de Enfermería. **Método:** estudio descriptivo, con enfoque cualitativo, realizado con ocho enfermeras de las clínicas de hemofilia de Ceará. Para la producción de datos, fue utilizado un cuestionario. Los datos fueron procesados por el Programa Microsoft Excel 2010, analizados por categorización temática. **Resultados:** se constató que 8 (100%) de las participantes de la investigación conceptuaron el SAE como siendo un “proceso o herramienta de trabajo, desarrollado para auxiliar y guiar la prestación de la asistencia”. **Conclusión:** fue posible identificar El deseo de estas profesionales sobre la necesidad de capacitación y estandarizar la SAE en la práctica asistencial. La implementación fue considerada como siendo una acción relevante, teniendo en cuenta los beneficios que podrá proporcionar a los pacientes, a los profesionales y a la institución. **Descritores:** Hemofilia A; Asistencia de Enfermería; Procesos de Enfermería.

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## INTRODUCTION

Hemophilia is a still unknown disease, usually hereditary, but it can occur without any family history. This makes relevant the approach to this theme for study. The person with hemophilia has bled for a longer period. This situation occurs due to a deficiency in the production of clotting factors (factor VIII in hemophilia A and factor IX in hemophilia B), which are proteins that help to stop bleeding. A person with hemophilia presents these factors in insufficient quantity to perform his function, thereby preventing the formation of clots that act in the interruption of bleeding processes.<sup>1</sup>

Data presented by the World Federation of Hemophilia, consider that this coagulopathy has the incidence of 1/10,000 children born male, and hemophilia A is more prevalent than hemophilia B, representing 80-85% of all cases. A survey conducted by the World Federation of Hemophilia in 2012 estimated that there are about 400,000 people with hemophilia around the world.<sup>2</sup>

This coagulopathy can be classified as hemophilia A, considered the most severe form of the disease, whose incidence is around 1/10,000 men,<sup>3</sup> and hemophilia B, which has an incidence 3-4 times smaller than hemophilia A.<sup>4</sup>

Data presented by the World Federation of Hemophilia Report that in Brazil hemophilia has an incidence of 1/5,000 live births male, that is, approximately 11,500 people throughout the country have the disease. Of this total, 9,500 have hemophilia A, and hemophilia B the number drops to 2,000 individuals.<sup>2</sup>

In Ceará, there is a total of five clinics of hemophilia, being located in Fortaleza capital, responsible for the overall coordination of all the work of the other units, and four clinics located in the municipalities of Crato, Sobral, Iguatu and Quixadá.<sup>5</sup>

The unit in Fortaleza serves 350 people with hemophilia, and of this total, 306 have hemophilia type A, and the other 44 have hemophilia type B; The Blood Center of Crato has 48 patients, 41 of hemophilia A and 7 of hemophilia B; Sobral Blood Center has 54 patients, in its entirety with hemophilia A; The Blood Center of Iguatu has 22 patients, 15 with hemophilia A and 7

with hemophilia B and the Blood Center of Quixadá has 7 patients, 5 with hemophilia A and 2 with hemophilia B.<sup>5</sup>

These units perform routine visits, dental treatment, physiotherapy sessions, the supply of coagulation factors in addition to providing guidance and training to patients and their families about the correct technique of dilution and administration of clotting factor. Patients are assisted by a multidisciplinary team consisting of nurses, doctors, social workers, psychologists, physiotherapists, orthopedic and dental surgeon.

All this assistance to people with hemophilia is necessary, given that, bleeding episodes may occur spontaneously or after trauma, varying the residual action of existing clotting factors in each. With this, it is instituted a severity rating that determines if hemophilia is Mild (5% to 40% factor activity); Moderate (1% to 5% factor activity); or Severe (<1% factor activity).<sup>1</sup>

A study in the hematology clinic at the blood center of Minas Gerais found that hemarthroses and rheumatoid arthritis are commonly identified complications in people with hemophilia attended the service.<sup>4</sup>

According to the Manual Treatment of Hereditary Coagulopathies of the Ministry of Health, the most characteristic clinical signs of this coagulopathy is bleeding, which may occur in the form of hematuria (blood in urine), epistaxis (removal of blood from the nose) melena (stool with presence of blood), hematemesis (vomiting of blood present), or contain as bruising, retro peritoneal bleeding and intra-articular (hemarthrosis), which is one of the most characteristic aspects of the severe forms of the disease. Hemarthroses affect most often the knee, ankle, elbow, shoulder, and hip.<sup>6</sup>

The diagnosis for the detection of hereditary coagulopathies is differential, as well as to evaluate the personal and family medical history of the individual, and assessing their clinical and laboratory findings.<sup>6</sup>

The treatment used for hemophilia is currently the replacement of the deficient clotting factor. The administration of the factors is performed most often by professionals of hemophilia clinics of hematology and transfusion centers. A measure adopted by the Ceará Blood Center aims to provide training for people with

hemophilia and/or their relatives, to encourage the practice of self-infusion of the factor. Thus, users are not restricted as to the health service. This measure aims to provide independence, freedom and autonomy of people with hemophilia, contributing positively to their quality of life.<sup>7</sup>

The injury prevention, the orientation of patients and the immediate treatment of bleeding, encouraging physical activity under the guidance of a health professional, attendance in clinical practice, guidance on the care with oral hygiene, as well as guidance on the importance of always carrying the hemophilia treatment center ID card, are extremely relevant measures to promote the health of people with hemophilia.<sup>5</sup>

The insertion of the Nursing Process (NP) in care practice is a fundamentally important tool for planning and more effective implementation of the care plan for the attention directed to the pathology of the subject but, in seeking to meet all his care needs to occur a better continuity of care to patients.<sup>8</sup>

Several nursing theories are used in the implementation of NP, such as Horta author of the Theory of Basic Human Needs, whose concept states that the human being has needs that must be met to obtain his complete well-being, which in turn, goes beyond attention to his medical condition. Therefore, it is much needed holistic care and individualized service to each customer. This care should be carried out mainly through the correct use of service tools, such as the use of nursing diagnoses and the prescription of nursing interventions.<sup>9</sup>

Some authors have developed their concepts to characterize the NP. The NP "is a dynamic and systematic actions interrelated whose focus is to assist the human being."<sup>9</sup> ... it is "the method used to deploy, professional practice, nursing theory."<sup>10</sup> The NP is an instrument for its correct use, needing the technical skills, scientific knowledge and critical thinking by the nursing professionals.<sup>11</sup>

A study aimed at evaluating the quality of life of people with hemophilia, the results showed that the NP has the advantage of its use to structure the practice of care, which brought benefits to assistance for patients, found as disadvantage the fact create a routine in

the service because the actions are restricted, critical thinking is not put into practice and thus ultimately slowing down the process of care, making it more difficult to assist the individual as a whole.<sup>12</sup>

It is essential that the process is prepared following all its stages, planning and development may vary according to the patients and their needs. Thus, its applicability may vary from patient to patient and professional to professional. However, the performance of all care steps is standard and should always be followed.<sup>10</sup>

For this reason, it is of paramount importance to the implementation of the NP in care practice, as it allows the provision of effective and continuous care nursing professionals in transfusion centers, so as a permanent tool that makes use of the NP to facilitate, organize, implement, monitor and prioritize patient care, it can be mentioned the Systematization of nursing assistance (SAE), which promotes the activities of the nursing team. Incorrect use of the SAE is committed to preparing the prescription of nursing care.<sup>13</sup>

SAE is a methodological model of organization, planning and implementation of health care activities carried out privately by a nursing staff, favoring patient care throughout the period in which he is under the assistance.<sup>11</sup>

All this systematization process is performed by the nursing developments, detection, and disease prevention, and evaluation of care through nursing records that enable the provision of changes in care, when necessary, thus aiming to meet the needs of patients and assist his family.<sup>10</sup>

The use of NP and implementation of SAE, are highly relevant actions to strengthen the healthcare practice of the profession, supporting the COFEN Resolution # 358/2009 which provides "the implementation and documentation of nursing process evidence of Nursing contribution in the health care of the population, increasing visibility and professional recognition."<sup>14</sup>

A study of patients treated at a hemophilia clinic in São Paulo found that it was possible to see that the correct use of the SAE has identified the main aspects that directly affect the quality of life of these individuals. The use of SAE as a guiding instrument action, provided a better performance of professionals on the

identified needs of nurses, thus favoring the care provided to patients.<sup>4</sup>

The correct use of SAE as an aid tool for decision making, implementation and evaluation of the assistance is extremely important for the entire care process, since its use benefit patients by improving care, benefit professionals who now have a tool that helps care activities, and the benefits provided to the institution which may have ways to evaluate the quality of service. The SAE is the exclusive competence of the nurse and ranges from implementation to evaluation.

It was a worry in the fact that the SAE is not present in care routine of any hemophilia clinics of Ceará. This led us to try to understand why the professional nurses do not have an instrument for their implementation with a view all the benefits provided proven with its use.

Thus, this study aims to assess the knowledge of nurses on the systematization of nursing care, as well as to understand the reasons why the SAE has not been implemented in routine care.

## METHOD

Descriptive study with a qualitative approach,<sup>15</sup> developed in the period of September-October 2014, in the State of Ceará, covering all hemophilia clinics located in the Hematology Center of the State. The municipalities included in the study were: Fortaleza, Crato, Sobral, Iguatu and Quixadá.

These clinics are responsible for providing assistance to some people with hemophilia, among other inherited bleeding disorders such as von Willebrand disease, factor deficiency V, VII, X, XII, XIII and combined disabilities.

The study included all professional nurses working in outpatient hemophilia of Hematology Centers and Hemotherapy of Ceará, totaling 9 professionals, distributed in units as follows: 3 in Fortaleza, 2 in Crato, 1 in Sobral, 1 in Quixadá and 2 in Iguatu.

At the end of the period of data collection, the nine professionals were invited to participate in the survey, eight of them returned the completed instrument.

As inclusion criteria, it was adopted the obligation of professional being a nurse of the service specifically hemophilia clinic,

and take part in the study by signing the free and informed consent form (TCLE). The exclusion criteria were determined when it would be impossible for any reason the communication process from verbal barriers to circumstantial barriers, or any other reason that could interfere with the study results.

The data were produced from a semi-structured form. During the months of September and October 2014, a printed paper was sent, attached to the TCLE, via pouch, to all nurses of hemophilia clinics of Hematology Centers of Ceara.

Before sending the instrument, e-mail to these professionals was sent as a way to call for voluntary participation in the research. This email aimed to present the professional relevance of the study, emphasizing not obligatory to be filling the questionnaire, as well as to guarantee the confidentiality of information collected, noting that the results at the end of the study are intended to assist a future implementation of SAE in service.

Completed the collection, the questionnaires were listed in ascending order according to their receipt. Microsoft Excel 2010 program was used for the preparation of a spreadsheet, which enabled organize, identifies, assess and extract the opinions of nurses on the issues addressed. It was adopted the code "E1" and so on, "E" representing nurse to name the opinions cited to preserve the identity of the participants.

Analysis of data was by thematic categorization, which according to Bardin, "it is a sort operation of the components of a set of differentiation, under a generic title because of the common characteristics of these elements".<sup>15</sup> While Fachin find categorizing "it is a process by which the student coordinates collected every observation or response that contains one or more set of categories, so that it can determine the frequency of occurrence or the response in each category."<sup>16</sup>

Initially, it was forwarded to consent term for the coordination of hemophilia clinic in the city of Fortaleza; this unit is responsible for the management of other clinics in the state of Ceará. That term had the objective of the study to assess the knowledge of nurses about the Systematization of Nursing Care and understand the reasons why the SAE has not

yet been implemented in the routine care of hemophilia clinics.

The collected data were kept in absolute secrecy, respecting the privacy of research participants.

The project was submitted for consideration by the Ethics in Research of the University Paulista Committee, following the rules governing research with human beings guided by the 466 Resolution of 12 December 2012 of the National Health Council and obtained the advice of approval under number 755353 on 08/14/2014.

## RESULTS

Of 8 (88%) nurses who participated in the study, there was a predominance of individuals over 26 years old, 8 female (100%), 6 married (75%), 8 with graduate (specialization, master's or doctorate) (100%) graduation time > 7 years with 4 (50%) and service time with the institution ≥ 5 years with 6 (75%).

The identification of these data was essential to characterize the profile of nurses working in hemophilia clinics.

### ◆ Category I: Systematic concept of Nursing Care and its use in the clinic of hemophilia

In the concept analysis, it was observed that both the nurses coordinator clinic as the regional clinics described the SAE as “a process or work tool, designed to help and guide the provision of nursing care.”

Complementing this concept, E<sub>4</sub> and E<sub>5</sub> also emphasize that “SAE is a private activity of the nurse, and therefore it cannot be delegated to other members of the nursing team.”

According to Nascimento, SAE operates as an organizational process in nursing care, providing grants to interdisciplinary and humanized methods of care, allowing to carry out a reasoned assistance in theoretical references.<sup>17</sup>

### Category II: SAE Steps performed in the clinic or why non-use it

As for use in clinics in some of the steps which the SAE is constituted, there was a divergence of responses. E<sub>1</sub>, E<sub>5</sub>, and E<sub>7</sub> considered that none of the SAE steps is used in providing assistance. E<sub>1</sub> justifies the non-use “*due to lack of knowledge of the benefits to the profession by using this process*” while for E<sub>5</sub>, not using the SAE is because “*we worked parallel to the*

*coordinator, we are waiting for implementation.*”

As for E<sub>2</sub>, E<sub>3</sub>, E<sub>4</sub>, E<sub>6</sub> and E<sub>8</sub> some SAE steps are carried out, but not in a standardized and systematic way, it is not a routine service.

The following statements confirm this that: E<sub>2</sub> “The clinical history, physical examination and nursing care was not the service organization to implement the SAE, with the establishment of nursing diagnosis, planning, and evaluation.” E<sub>4</sub> “Yes. We use history, implementation, and evaluation of performed guidelines. The systematization of nursing care in our Blood Center does not happen in a standardized way.”

To Tannure and Pinheiro, NP is operated in stages, which are interrelated and follow the following sequence: research, nursing diagnosis, planning, implementation and evaluation assistance.<sup>10</sup>

### ◆ Category III: Concept by the Nursing Process

Regarding the steps of NP, 7 (87.5%) of professionals contextualize “the process consists of five steps: history, nursing diagnosis, planning, implementation, and evaluation.” E<sub>4</sub> describes in detail all the stages of the NP “History: Survey of meaningful information to the nurse who makes possible the identification of diagnosis and nursing problems; Diagnosis: where there are conditions identified that generate actions/nursing care; Planning and implementation: it is the development of actions to be performed and recorded; Reviewed analysis of the responses provided by the patient, which determines whether the actions/nursing interventions reached the expected result.”

Moreover, starting from this understanding, E<sub>5</sub> reports that the NP steps are “history, diagnosis, and the implementation of actions” and that “not even use it, we forget a little.”

For Tannure and Pinheiro, the NP is considered a key method for performing a care practice of nursing, based on a theoretical reference, divided into five interrelated steps: research, nursing diagnosis, planning, implementation and evaluation of results.<sup>10</sup>

The performance of this process is of great importance as it contributes to the development in the scientific field of nursing. Nurses have a key role in the

delivery of patient care, always seeking to meet their health needs, and when it appropriates the practice based on scientific knowledge, allows the further strengthening of the category.

◆ **Category IV: User Experience SAE at another institution**

When asked about experiences with SAE, 7 (87.5%) of professionals said they had never used the SAE in their care. E<sub>1</sub> contextualizes his previous experiences as follows: *“The SAE was guided by the nurse through the collection of patient information, prescription of nursing interventions by nurses through a predetermined checklist. However, there was an evaluation of the actions performed by the nursing staff. I think that the SAE was not carried out completely and correctly.”*

The provision of the assistance becomes only the performing of procedures that require greater technical and less critical reasoning that seeks to prevent an appreciation of nursing as a science.

This can be confirmed by a study conducted in 2008 in the state of Santa Catarina, which aimed to understand the meaning of SAE in a multidisciplinary team. It was found that the fact that the nursing activities are carried out only as a routine service, which has led to accommodation by those professionals who have adopted the

“disciplinary culture without, however, reflect on new possibilities to be and act in everyday micro-spaces.”<sup>17</sup>

◆ **Category V: Implementation Responsibility of SAE in outpatient clinics**

The professional nurse was considered responsible for the implementation of SAE in service for 5 (62.5%) of the study participants.

E<sub>3</sub> states that the responsibility for implementation “is up to the coordination of services to start the implementation process, along with the team.” While E<sub>5</sub> and E<sub>6</sub> say “is nursing team responsibility the implementation of the SAE in service.”

Considering the SAE is a private activity of the nurse, the systematization of care allows them to define the role of nurses in their work space since it allows the application of scientific mode of knowledge, organized and systematic.<sup>10</sup>

◆ **Category VI: Benefits provided to professionals and people with hemophilia by implementing SAE**

This category showed a diversity of views as a result of this theme. For this reason, nurses' view is displayed as a table to allow a better visualization of the data (Table 1).

Nurses	Opinion
E <sub>1</sub>	<i>“To guide the activities and improve care.”</i>
E <sub>2</sub>	<i>“To organizing assistance, favoring comprehensive care.”</i>
E <sub>3</sub>	<i>“It Qualifies care and improves the visibility of nursing.”</i>
E <sub>4</sub>	<i>“Individual attention to each patient, learning about the need that the practice requires.”</i>
E <sub>5</sub>	<i>“More practical actions, with far more efficient responses to patient needs.”</i>
E <sub>6</sub>	<i>Organized assistance with a single language, patients will gain because in all blood centers, the language will be the same”.</i>
E <sub>7</sub>	<i>“The ability to solve problems, make decisions, predict and evaluate the consequences.”</i>
E <sub>8</sub>	<i>“Credibility with the team and hemophiliac a certainty of quality service.”</i>

Figure 1. Benefits provided to professionals and people with hemophilia by implementing the SAE. Fortaleza - CE, 2014.

Despite the diversity of their responses, it was unanimous opinion that the implementation of the SAE in the service

had enabled a number of benefits to professionals as it allowed guiding the activities, had provided an efficiency of

care and the ability to solve problems, and to be considered a standard of quality of service, thus favoring for better visibility of nursing.

Among the benefits provided to people with hemophilia, it has been considered the possibility of a systematic, comprehensive care, enabling a higher quality of care provided.

Improving care is the result of an integrated and systematic management action that favors the development of the practice of the activities of nursing professionals.<sup>10</sup> Thus, the inclusion of guiding instruments that help care is extremely important to achieve satisfactory results regarding care people with hemophilia.

#### ◆ Category VII: Tip of professionals to implement the SAE

The completion of professional training on the subject was reported to be a key factor for future implementation. According to E<sub>4</sub>, the updating of professionals is extremely relevant *"as it encourages the development of actions and makes the installation and implementation of the nursing process easier in the care of our patients. It would be important for planning future actions, to implement an effective nursing process in our blood centers."*

However, E<sub>2</sub> reports that "This intention is old. We lack a greater organization of our time to dedicate to this implementation."

The suggestion of E<sub>1</sub> based on "To meet the nursing professionals to talk about it; create tools (questionnaires) to guide the actions to be performed (even realize what the most common nursing diagnoses for people with bleeding disorders), evaluate nursing interventions most common and necessary for this type of people and evaluation of these activities. After creating these instruments, a pilot test should be conducted for possible adjustments."

It was clear that in view of these professionals to occur successful implementation of the SAE in outpatient clinics, two aspects are extremely relevant: the qualification and evaluation of nurses on the subject, in addition to the preparation of collective project allowing everyone to come to participate in this implementation.

## DISCUSSION

The profile of the sample found that the study participants as a whole had a course graduate, demonstrating the importance of these professionals and their qualifications. The completion time of the strength of more than 7 years was reported by 4 (50%) of nurses, and it has highlighted that some concepts or more specific subjects may be out of date compared to the period in which they were experienced at graduation. The service in the institution was of great importance for the study, as identified if at some point the implementation of the SAE was contemplated by the nursing staff.

The perception of the nurses to SAE concept is extremely relevant because, from the moment they see the actual knowledge of the professionals on the specific theme, it helps to identify which prevents the use of SAE in the service, and to understand why the systematization was not implemented in the service until the time.

Regarding the stages of SAE, there was a conflict of opinions, 3 (37.5%) of nurses said that the SAE was not inserted in the actions of the nursing staff of hemophilia clinics while 5 (62.5%) of nurses consider that the implementation of the SAE will not occur until the moment. Therefore, its performance does not happen completely, only some of its steps are performed during the provision of care.

As the description of the nursing process and its stages, 7 (87.5%) of the nurses conceptualized the NP with its five stages, emphasizing its importance across the assessment of actions taken by the nursing staff. The use of this instrument allows the nurse appropriates her function, using the scientific knowledge to contribute then to nursing practice based.

Concerning the experience of these professionals with the SAE, 7 (87.5%) said they have worked in a company which used since instrument in the service routine. This supports for non-implementation of SAE in outpatient hemophilia, given that despite having professional knowledge of the benefits of its use, this is a topic that does not match the experiences of the same practice.

By the responsibility for implementation of the SAE in the service, the nurse was cited by 5 (62.5%) of the participants.

In the benefits provided with the implementation of the SAE, the nurses said, SAE is a guiding instrument of activities, which organizes and improves care by strengthening the individual patient care, allowing an organized care where all blood banks have provided a service standard that should be directed to meet the needs of each patient according to their care needs. Moreover, with all this care, people with hemophilia treated in clinics will give credibility to the nursing staff.

As suggestions for implementing the SAE, there was training on this theme to update professionals, thus encouraging the development of actions and future projects to assist the implementation. Thus, for this process occurs effectively, a meeting with the nurses of all hemophilia clinics of Ceará is necessary to discuss the needs of the front unit to the identified difficulties.

## CONCLUSION

This study allows us to conclude that by identifying the nursing team disabled the non-use of SAE, it was possible to resume, the importance of its concept and its benefits.

These benefits of its use go beyond favoring care practice based on methodological theories. Its use envisions a carefully directed to the individual needs of each patient, objective better care to provide quality of life for people with hemophilia treated in clinics. Thus, the nursing records, identification of nursing diagnoses, the development of interventions and care requirements, can be performed reliably and standardized according to the characteristics of each patient.

The improvement of nursing care provided in hemophilia clinic is a crucial factor in achieving the quality of life of people attended the service. Given that, hemophilia has no cure until today, and the individuals of this coagulopathy remained linked to the service throughout their life.

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