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Abstract

The challenge to improve the treatment of Sickle Cell Disease (SCD) is to plan for managers and health professionals, as well as to estimate the necessary costs. To this end, research should be developed to support the health area, with emphasis on the development of software that complements data collection. For these reasons, the objective of this study is to describe the development of software for the collection of cost information and clinical, laboratory and therapeutic data of patients with SCD, which can be used in the future by other areas of health. This is an experimental and applied research focused on technological production. The applied process model was incremental and followed the steps of communication, planning, modeling and development. The first version is in the testing phase and presents the record format, does not require internet connection, can interact with Windows®, Linux® or MacOS® operating systems and encrypt data for storage. In the next increments, the customization of the fields with a broad structure for data collection; data export in spreadsheet format for use in external tools; creation of customized reports and central database stands out.

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Developing *software* IVO for clinical, laboratory, therapeutic and cost data collection for Sickle Cell Anemia.

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Abstract

The challenge to improve the treatment of Sickle Cell Disease (SCD) is to plan for managers and health professionals, as well as to estimate the necessary costs. To this end, research should be developed to support the health area, with emphasis on the development of software that complements data collection. For these reasons, the objective of this study is to describe the development of software for the collection of cost information and clinical, laboratory and therapeutic data of patients with SCD, which can be used in the future by other areas of health. This is an experimental and applied research focused on technological production. The applied process model was incremental and followed the steps of communication, planning, modeling and development. The first version is in the testing phase and presents the record format, does not require internet connection, can interact with Windows®, Linux® or MacOS® operating systems and encrypt data for storage. In the next increments, the customization of the fields with a broad structure for data collection; data export in spreadsheet format for use in external tools; creation of customized reports and central database stands out.

Keywords: *Technology; Software; Cost analysis; Sickle cell anemia.*

1. Introduction

Sickle cell anemia (SCA) is the most common monogenic hereditary disease in Brazil, whose prevalence is higher in the north and northeast regions, affecting 6 to 10% of the population, while in the south and southeast regions it affects about 2 and 3% of the population respectively [1].

SCA spread was initially concentrated in tropical and subtropical areas due to selective genetic changes against Malaria. Because of the current population migration, a large number of children with SCA are

found in the European and American continents, the latter more specifically in North America [2].

SCA represents the most severe form of Sickle Cell Diseases, with structural variation in hemoglobin that becomes sickle-shaped (drepanocytes). The clinical effect of this change may lead to hemolysis or vaso-occlusion, triggering inflammatory processes and tissue lesions in the early years of life, which tend to increase severity over the years in conditions that can be fatal [3].

The diagnosis of SCA results from the analysis of hemoglobin in laboratory tests to ascertain structural abnormalities. The main techniques used are the Hemoglobin Electrophoresis by Isoelectric Focusing (IEF) and High Performance Liquid Chromatography (HPLC) [4].

Folic acid supplementation and antibiotic prophylaxis are recommended from the diagnosis to the age of 5 years, period of greatest occurrence of deaths in children affected by the disease. Care is also recommended with regard to diet, hydration, special immunization schedule and appropriate treatment for pain crises and acute events [5].

As a treatment option for SCA there is in the curative modality the allogeneic hematopoietic stem cell transplantation, with limited donor availability and in an unconventional way. The main treatment alternatives do not lead to cure, that is, chronic blood transfusion or exchange transfusion as adjuvant to symptoms or the only indicated pharmacological therapy that comprises the use of Hydroxyurea [4, 6].

The highest mortality rate occurs in children and young adults, mostly due to cardiac causes, sepsis, stroke, acute respiratory insufficiency and multiple organ failure [7, 8].

The challenge for improving the treatment quality for SCA is the planning enhancement of managers and health professionals, as well as cost estimates and economic benefits required to improve care. In addition, the need to setting up a database in the healthcare network in order to outline the creation and structuring of specialized and multidisciplinary services of quality for outpatient care for SCA patients [2, 8, 9].

The costs of treating SCA patients are still poorly discussed and in many countries unknown. Some researches indicate that the estimated total costs increase with these patients' age and the complications resulted from the disease, therefore the hospital expenses only tend to increase [10, 11].

In Brazil, much still might to be invested and studied to optimize the cost analysis with regard to the treatment established for SCA, thereby subsidies can be generated to support public policies in favor of patients and society.

In view of generating support for health research, the importance of developing *software* to aid and complement processes of data collection and analysis processes, which can combine multiprofessional knowledge from different areas. Research support can ensure the agility, organization and production of large databases of information in real time or in the shortest timeframe, ensuring the highest quality of data collected and acceptable safety margins [12, 13].

Due to the constant requirement for optimization of clinical, epidemiological and health economics research, innovation in health data collection procedures can be achieved through the use of technologies that support researchers and health professionals, through *software* that ensures quality and safety in the collection, storage and constitution of systematized databases [14].

In this sense, the objective of this study is to describe the development of *software* for the collection of clinical, laboratory, therapeutic and cost data of patients with SCA, which may be used in the future by other health areas to collect, organize and store data.

2. Materials and methods

It is an experimental and applied research focused on technological production with a view to generating a product. The proposal was designed to develop software for collection of cost information, clinical, laboratorial and therapeutical data from patients with sickle cell disease.

The *software's* principles are: optimize aid, computerize and standardize health data collection, with encrypted storage in a database. Initially, it will assist you in the development of researches of the Center for Interdisciplinary Studies in Sickle Cell Disease - NEIDF (Núcleo de Estudos Interdisciplinares em Doença Falciforme) of the Federal University of Mato Grosso do Sul and it was named IVO in honor of the research group coordinator.

The project and its implementation took place at the *IF Make*r laboratory of the Federal Institute of Mato Grosso do Sul and at the Epidemiological Studies Laboratory of the Medical School of the Federal University of Mato Grosso do Sul, both in Campo Grande, from July to October 2019.

The process model applied for software development was the incremental, which progressively provides a series of prototype versions, called increments, as a set of features is finalized [15]. The first increments are functional versions of the *software* that meet basic user requirements. From their use and / or evaluation, additional features and functionality are planned and developed.

Following are the steps of the *software* IVO development process.

2.1 Communication and Planning

This step was performed to understand NEIDF needs and define the expected functions and characteristics of the product to be developed. In addition, the resources and techniques to be used in the development process were defined.

To identify the system requirements, in other words, the functions expected from the software, meetings were held with a multidisciplinary team composed of researchers in health and computer science.

The initial requirements were motivated by the forms developed by NEIDF over the years and applied in paper format for data recording [7]. The first increment of the *software* was this form restructured by the researchers and then organized into digital format.

The variables identified in the form refer to the patient's personal and clinical data, such as identification, family history, demographic data, clinical data, treatment, and hospital admission data with subdivision in length of stay, reason, blood transfusions, medications, intensive care, imaging exams, laboratory tests, surgeries, and treatment costs.

NEIDF researchers pointed to the need to use the *software* without the obligation to connect to the Internet, considering the possibility of the inexistence of the connection at the time of data collection. Thus, it was defined for the first version by *desktop software*, that is, it is directly installed on the personal computer and works only on it.

Another motivation for the *software* to be *desktop* was the recent change in the Brazilian legislation on data protection, including data in digital media, instituted by law Nº. 13.709 / 2018 [16]. By leading a *desktop* version, data will not be available for access from anywhere or from any computer.

Although the initial *software* restriction may only be available on a user's personal computer, it is a

necessary security measure for data protection.

2.2 Modeling

Modeling is the stage in which the *software* engineer creates the models to better understand their needs [15]. In this phase the requirements are modeled and the *software* rules that precede the development process are defined.

Considering that software IVO will run locally on a *desktop* computer and that there is the need the users' use on different computers, a structure has been modeled that allows it to be installed on multiple machines. There is an additional option so that the data collected on each computer can be sent to a central database. The structure of the IVO software follows as shown in Figure 1 below.

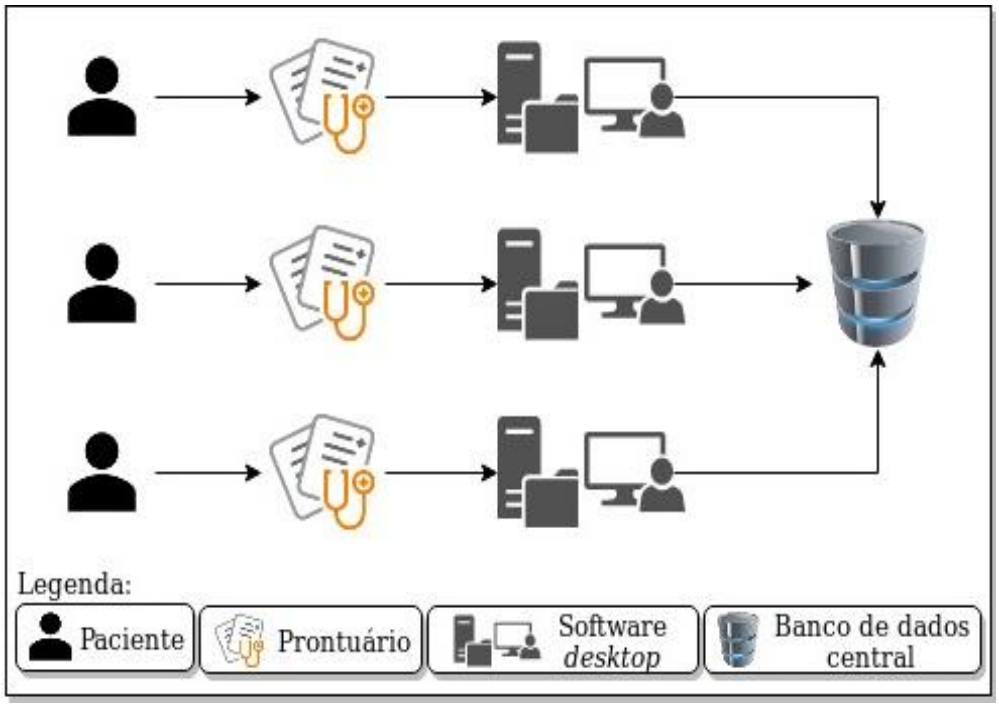

Figure 1. Operating structure of the *software* IVO. Campo Grande / MS, 2019**.**

Another indication of the NEIDF team was the possibility of using *software* to collect data from other clinical cases, besides those involving only SCA. Therefore, the data collection forms were modeled to allow the user to configure them for use in other health specialties and thus to organize their collections safely and effectively.

2.3 Development

The development consists of the *software* code generation stage, that is, the transformation of the models into a programming language, as well as the tests to detect possible coding errors [15].

The programming language chosen was Java, which is used through the set of appliances for application development (JDK), provided by Oracle. The database management system applied was MySQL, responsible for storing and retrieving system data.

In the first increment the system presents a home screen for the user to authenticate with his personal

password. Once logged in, on the main screen, there is the option for the user to register a new patient, enter the medical records, and parameterize cost valuesfor calculations or to consult the registered medical records.

To validate the *software* functions, unit tests were performed to verify that the source code was correctly implemented.

3. Results and discussion

The first version of the *software* IVO, a digital tool for cost information and collecting clinical, laboratorial and therapeutical data from Sickle Cell Disease patients, has been finalized and it is available for testing by researchers. Figure 2 presents the system startup screen when database data is loaded.

Figure 2. Screen of startup of the system IVO. Campo Grande/MS, 2019.

The current version replaces the paper form previously used by NEIDF researchers for data collection. Figure 3 shows the beginning of the registration of a patient's record when the initial record data is requested for storage.

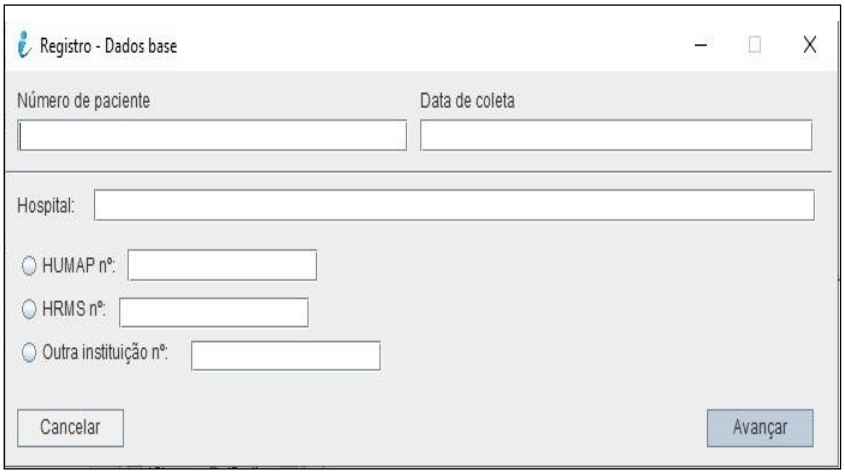

Figure 3. Initial screen for registering the patient's medical records in the System IVO. Campo Grande / MS, 2019.

The system IVO allows the retrospective data extraction available in already existing medical records or from structured interviews that may take place with patients and / or the community, this activity may occur directly using a computer with the tool installed.

The application requires no connection to internet, for the data, feed occurs in a database installed directly on the computer used. In addition, the *software* is Cross-platform, that is, it can be used on computers that run *Windows®, Linux®* or *MacOS®* operating system.

For access to the *software,* it requires password authentication, which is provided individually for each user of the registered system. Patient identification data is encrypted to ensure the security and legality of the *software* before being stored in the database.

It is worth noting that the data collection of patients' medical records with Sickle Cell Disease from a doctoral thesis will serve as the basis for the system IVO tests and their possible adequacies. Such research has already been duly authorized by the Research Ethics Committee of the Federal University of Mato Grosso do Sul, under protocol number 2,892,100 of September 13, 2018.

The main limitations of this research are related to the need of new tests, for adjustments and optimization of the *software* release for application in the field by the researchers, as well as the implementation of new functions for the release of the System IVO to be used by other researchers in researches alike.

Among the features to be implemented in the next increments of the system, the following should be highlighted:

- The personalization of the fields that comprises each form, providing a broad structure for data collection and the possibility of research from other health areas to apply the product.
- The option to export data in spreadsheet format for use in external tools, such as *Microsoft Excel®,* reducing the risk of errors in data transcription by researchers.
- The creation of a personalized report with textual, graphic and statistical presentations of the collected data.
- The creation of the central database for synchronization of data stored on local computers.

There is a need to arouse interest in the development of new technologies such as *software* and applications that can be designed to the practice of data collection for research, treatment and support for healthcare professionals and patients. This vast field still needs investment, new research and innovative practices [13, 14].

4. Conclusion

The collection of field data is a common practice in research work in the health area and is often done manually on paper, which are subsequently transcribed in digital format, especially in spreadsheets for analysis.

The *software* developed can optimize and reduce the researcher's rework, provide quality and in order to minimize the inconsistencies in the collected data.

From the ethical and legal point of view, it provides greater protection of digital data, a fundamental fact in the 4.0 health era, through cryptography techniques and security policies that ensure the confidentiality, integrity and availability of data to those involved in research.

The *software* can also generate a cost base for treatment and optimize the development of cost analysis work within the area of health economics.

There is a need for implementation and completion of the IVO *software*, so that it can be hosted in an online server in an open manner and thus be used by several researchers in favor of improving the health conditions of populations with sickle cell disease or other health changes.

5. Funding

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