Research Article

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Information system for assessing and monitoring patients with fibromyalgia syndrome – multidisciplinary approach.

Sistema de informação para a avaliação e monitoramento de pacientes com síndrome da fibromialgia - abordagem multidisciplinar.

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Abstract

Introduction: Fibromyalgia Syndrome (FMS) is characterised by chronic widespread pain and tender points on palpation. FMS is associated with depression, anxiety, fatigue, sleep disorders, and functional bowel disorders that can intensify painful feelings, altering functional capacity and quality of life. The health provider usually identifies these conditions through assessment and monitoring tools and recordsthe results on paper. Failure to use electronic information systems, which have specific methodology for the integration of Health Information Systems, hampers the applicability of these methods in clinical practice and does not allow visualisation and comparison of the results in a simple manner. **Objective**: To propose an information system for assessing and monitoring patients with FMS (SISFIBRO). **Method**: The first phase consisted of data collection to select evaluation and monitoring methods used by doctors, physical therapists, rheumatologists, and specialists in fibromyalgia. Next, we performed the modelling of the system in the Unified Modelling Language (UML). Based on the diagram of classes, we performed conceptual data modelling with entity-relationship diagrams. The prototype was implemented with the SISFIBRO Oracle database. Below, we included data from 36 patients with FMS to analyse whether the system provided all of the information and necessary functions. **Results:** In Brazil, most of the professionals (82.4%) record and store patient data on paper charts, and 17.6% do so using electronic systems. The most widely used instruments and methods arethe visual analogue scale (VAS) SF-36, theFibromyalgia Impact Questionnaire (FIQ), evaluation of tender points according to the American College of Rheumatology (ACR), and the Beck Depression Scale; all are available in SISFIBRO. We developed 1 diagram of use, 1 diagram of classes, 6 diagrams of objects, and 5 diagrams of sequences. We decided that SISFIBRO must be integrated with the Electronic Health Record (EHR) for the recording, storing, sharing, and retrieving of the information. This integration will assist in the clinical practice of health professionals. **Conclusion**: It was possible to create a system with the reliability needed to support and improve the assessment and treatment of FMS.

Keywords: Information Systems, Fibromyalgia, Physical therapy, Electronic Health Record Information Storage and Retrieval.

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INTRODUCTION

Fibromyalgia Syndrome (FMS) is a painful condition of unknown origin that is prevalent in females. FMS presents with chronic widespread pain and tender points on palpation. Moreover, FMS is associated with fatigue, headaches, sleep and psychological disorders, and functional bowel problems.(1) In 1990, the American College of Rheumatology (ACR), based on studies by Wolfe et al.(2), established diagnostic criteria for fibromyalgia syndrome, which are currently in force.

In addition to chronic widespread pain and tender points on palpation, other factors contribute to the diagnosis and monitoring of patients with FMS, including depression, anxiety, fatigue, and sleep disorders. These conditions can significantly alter the levels of pain in the patients and their quality of life.

The conditions can be identified and quantified through the clinical history of the patient and by evaluation and monitoring, mostly in the form of questionnaires, which differ in certain respects. These instruments help to assess and monitor the progress of patients. The presentation of progress using a paper form hampers its applicability becausea patient or clinical worker needs to take the time to fill outthe form and to tabulate the results. Moreover, the large amount of information to be collected makes errors in the data collection and recordings possible. The use of paper charts is not just restricted to Brazil. In developed countries such as Belgium, there is still a need to encourage physical therapists to use computerised systems for data storage and evaluation of their patients.(3)The authors believe that these workers will begin to use the electronic medical records only if this tool can actually facilitate their clinical practice, bringing a positive return to their daily practice.

With the increasing development of information technology, health care has benefited from the installation of information systems. These systems promote the optimisation of medical care as well as the recovery and storage of data; they also help in the study of demographics and health populations, thus facilitating epidemiologic surveillance.(4)This advantage, according to the authors, was realized after the design of the national health care information system, which facilitated the speed and agility of the production of health information. In some countries, health information systems are well structured and integrated. In Brazil, SISare designed for institutions of research and still lack the proper standardisation to be integrated into the clinic, which would allow the interoperability and sharing of information.

Even with the advance of health informatics, most of the recorded information in the field of physical therapy is on paper charts. The various conditions that may be associated with FMS makes this form of registration ineffective in helping the professional because of the lack of practicality in data collection and visualisation of their results.

This study had as an objective the development of an information system to assist health professionals in assessing and monitoring clinical and therapeutic activities for patients with FMS.

METHODS

This study was divided into two phases.

Phase I - Definition of Data

This phase was based on literature search data from the study by Camargo, Bastos, and Moser(5), whichselected tools that were commonly used by researchers for the assessment and monitoring of FMS over the last ten years. In addition, evaluation tools associated with chronic pain and terms related to information technology were selected. From this step, we defined the data and the requirements of SISFIBRO, and then we set up the sample and the ethical aspects of the research.

Development of the instrument for data definitions and requirements of SISFIBRO

With the identified data, we have created a form for collecting information regarding the data characteristics. This data entry form fits the system specifications. Also included on the form is the identification of the use of tools by health professionals in their clinical practice. We also included questions to determine how information was recorded and stored in the clinical environment and the treatment environment. We also included questions that identified the profile of the professionals who participated, such as personal data, academic background, and area of expertise.

The sample consisted of 6 rheumatologists and 11 physical therapists, totalling 17 professionals.

The selection of rheumatologists was made through a study of the Brazilian Society of Rheumatology (BSR) (www.reumatologia.com.br). A search was then conducted on the Curriculum Lattes (CNPq, 2010, www.cnpq.br) to check whether these professionals were involved in FMS.

For the selection of the physical therapists, research was conducted at universities with graduate programs because these professionals do not have a record that identifies their training area. Then, we performed an analysis of the profile of the Curriculum Lattes of the professional to certify his/her involvement with FMS.

As criteria for inclusion of these professionals, we selected the following: rheumatologists and physical therapists who had been working with patients with fibromyalgia syndrome for a minimum period of 12 months in clinics, hospitals, and institutions of higher education.

The project was approved by the Ethics in Research of PUCPR in August 2009, with protocol number 5120 and resolution number 0003126/09.Practitioners who agreed to participate in the study signed an informed consent (IC), which included the research objectives and details of their participation as volunteers.

The sample used in the analysis in the SISFIBRO was comprised of the charts of 40 patients, 22 from the Physical therapy clinic of PUCPR and 18 from an association of fibromyalgia (FIBROCURITIBA - www.fibromialgia.com.br).

In this sample, 8 patients were evaluated according to the criteria of the American College of Rheumatology (ACR); these 8 patients answered the Fibromyalgia Impact Questionnaire (FIQ) and the visual analogue scale (VAS). The other 14 patients were evaluated to identify the tender points and responded to the VAS.

From the group FIBROCURITIBA, 9 responded to FIQ, and the other 9 responded to the Quality of Life Questionnaire SF-36, the Beck Depression Scale, and the VAS.

The forms were randomly distributed to the participants of the group, and questions were answered by the researchers. The data were entered directly into the database to test the prototype and feasibility of completion of the SISFIBRO.

Contact with the experts, who worked in the city of Curitiba, was made by email or phone, and interviews werescheduled. After acceptance, the form and consent were sent, andafter they were signed and returned, the data collection was started.

The data were analysed and scored, and the total score was given by the sum of the scores obtained on each category. The questions were organised into 20 worksheets in Microsoft Office Excel 2003, and they were statistically analysed. The statistical test chosen was the Fisher exact test ($p < 0.05$) because the sample size was 17 ($n < 30$). There was no statistical difference in the selection of methods of evaluation and monitoring among the rheumatologists and the physical therapists ($p < 0.05$), so the population was presented as health professionals or experts.

For the selection of instruments to compose the SISFIBRO, we excluded those that obtained a percentage above 50% for the item "never utilised". The instruments of evaluation and monitoring were also organised in order of importance so that instruments 1 to 4 corresponded to the highest degree of importance and numbers 5 to 8were of less importance.

System Requirements

The functional requirements that were considered were access to the information system (login and password), the selection of methods forthe evaluation and monitoring by health professionals, the answering of questionnaires by patients and/or health care professionals, and verification and analysis of the results by a health professional. Non-functional requirements corresponded to the environment, the form, and when the SISFIBRO would be used.

System Modelling

The modelling of the system to access the database used the UML with the tool JUDE Community. Thirteen diagrams were developed, which corresponded to 1 use case diagram, 1 class diagram, 6 diagrams of objects, and 5 diagrams of sequence.

The conceptual modelling of data was performed based on the class diagram, utilising entity-relationship diagrams from the tool ERwin 4.0. After defining the system requirements and the modelling of SISFIBRO, the implementation of the information system was started.

Phase II - Implementation of SISFIBRO

The entity-relationship diagram (RSD) was converted into tables constructed using the structured query language (SQL), which is the standard language used for relational databases(6), and the Oracle Database (http://www.oracle.com). This software was chosen to allow data access from any computer terminal connected to the Internet by promoting the sharing of information among users.(7) There were 21 tables in the database.

Afterwards, the SISFIBRO was instantiated with patient information to verify the need for changes in the physical design, indexing, and reorganisation of the allocation of the data.

RESULTS

Definition of data

Of the professionals who participated in the study, 82.4% were female, 17.6% were male, 64.7% were not older than 40 years, and 35.3% were over 40 years. Among these professionals, 64.7% had expertise in rheumatology, and 88.2% hadover five years of experience in the area. Moreover, 64.7% had more than 10 years of experience with FMS.

Regarding the method of recording data, 100% of the professionals performed evaluations and/or re-evaluations most of the time or always. Of these, 82.4% recorded and stored patient data in paper records, and only 17.6% used an electronic form.

The evaluation of tender points was performed by means of digital pressure by 86.7% of the professionals,whereas 13.3% utilised the dolorimeter. The record of tender points was accomplished usinga textual description of the points for 58.3% of the professionals, and a printed drawing of the map of pain or manual design was used by 41.7%. Most professionals, 94.1%, assessed pain by the VAS scale.The quality of life was assessed by 82.4% through the FIQ. Only 35.3% of the specialists assessed anxiety and used the State-Trait Inventory Anxiety. Depression was assessed by only 29.4% of the specialists, and the sleep quality of the patients was assessed by 47.1% of the specialists.

The percentages corresponding to the use of assessment and monitoring tools were the following, in descending order: 94.1% for VAS, 88.2% for SF-36, 82.4% for FIQ andfor tender points evaluation, 64.6% for the Beck Depression Scale, 35.3% for the State-Trait Inventory Anxiety, 23.5% for the McGill Pain Questionnaire, and 11.8% for a Sleep Inventory.

In order of decreasing importance in the scoring from 1 to 4 (Table I), we obtained 100% for the VAS, 94.1% for FIQ, 87.5% for the evaluation of tender points according to the ACR, 71.4% for SF-36, 23.1% for the Beck Depression Scale, 15.4% for the McGill Pain Questionnaire, 8.3% for the State-Trait Inventory Anxiety, and 7.7% for a Sleep Inventory.

System Requirements

During a survey of SISFIBRO requirements in relation to completing the tools by the patients in paper form and in the electronic system, we observed that 58.8% of the professionals think that the patient would be able to fill in the tools in the paper form themselves. Regarding the electronic medical record, 70.6% believed that the patient cannot fill out the forms without assistance from health professionals.

Regarding the selection of methods for evaluation and monitoring, 82.4% of the professionals suggested that these should appear on the screen with the name of the instruments of evaluation and monitoring, requiring the health professional to click on the name of the instrument to be completed. Furthermore, 76.5% of professionals suggested that each method of evaluation and monitoring should have separate areas to include their information.

Table 1. Order of importance of assessment tools.

Question	All professionals		Rheumatologists		Physical Therapists		p* value (rheumato X phys. therap)
Visual Analogue Scale - VAS							
1 a 4	16	100.0%	5	100.0%	11	100.0%	x
5 a 8	0	0.0%	0	0.0%	0	0.0%	
FIQ							
1 a 4	16	94.1%	6	100.0%	10	90.9%	p=1
5 a 8	1	5.9%	0	0.0%	1	9.1%	
Evaluation of Tender Points							
1 a 4	14	87.5%	6	100.0%	8	80.0%	p=0,500
5 a 8	2	12.5%	0	0.0%	2	20.0%	
SF-36							
1 a 4	10	71.4%	2	50.0%	8	80.0%	p=0,521
5 a 8	4	28.6%	2	50.0%	2	20.0%	
Beck Depression Scale							
1 a 4	3	23.1%	2	50.0%	1	11.1%	p=0,203
5 a 8	10	76.9%	2	50.0%	8	88.9%	
McGill Pain Questionnaire							
1 a 4	2	15.4%	0	0.0%	2	20.0%	p=1
5 a 8	11	84.6%	3	100.0%	8	80.0%	
State-Trait Inventory Anxiety							
1 a 4	1	8.3%	0	0.0%	1	11.1%	p=1
5 a 8	11	91.7%	3	100.0%	8	88.9%	
Sleep Inventory							
1 a 4	1	7.7%	0	0.0%	1	10.0%	p=1
5 a 8	12	92.3%	3	100.0%	9	90.0%	

* Fisher's exact test $p<0,05$

Regarding the time of completion by patients and/or health care professionals, 52.9% of the professionals suggested that the patient should not complete the assessment methods alone, and 29.4% thought that the assessment methods should be completed before consultation while in the waiting room. In addition, 5.9% suggested that the patient should complete the evaluation at the end of the consultation in the presence of a health professional, but without their help, or even at the beginning of the consultation alone or during the consultation with help.

Specification of the SISFIBRO

The SISFIBRO must be integrated with the electronic patient record (EPR). To this end, it must contain the essential core of the clinical data set established by theStandardisation of Clinical Records - PRC (SOP 001/98), which consists of identification data and relevant clinical data of the patient, allowing the sharing of information with the various health systems. Integration with the EPR permits the information contained in the records of Rheumatology and Physical Therapy to be used or related to SISFIBRO and enables other systems to access the recorded and stored information, which reinforces the importance of the PRC. Usually, the electronic patient record is designed to meet the needs of the medical record, often based on ICD-10 or ICD-9. The information needed for epidemiologic monitoring and research should be generated from data stored in SISFIBRO and should not include any specific field in the system. From the results of the research, it was decided to keep 5 of the 8 methods of evaluation and monitoring from the literature. The State-Trait Inventory Anxiety, the McGill Pain Questionnaire, and the Inventory of Sleep with percentage of utilisation below 50% were excluded. We found that SISFIBRO should allow for the completion of the five methods of evaluation and monitoring. However, the professional can select which will be answered, and it is not mandatory to complete all of the methods each time. The patient must be accompanied by a health professional to clarify his/her questions. If health professionals deem it possible, the patient may fill it out alone, but the expert should define the methods of evaluation and monitoring.

The functionality of SISFIBRO, its data entry in digital format, and the recovery of information are the following: access to the system through login and password; selection of the questionnaires by health professionals; answering the questionnaires by the patient or health professional; and verification and analysis of the results by the health professional.

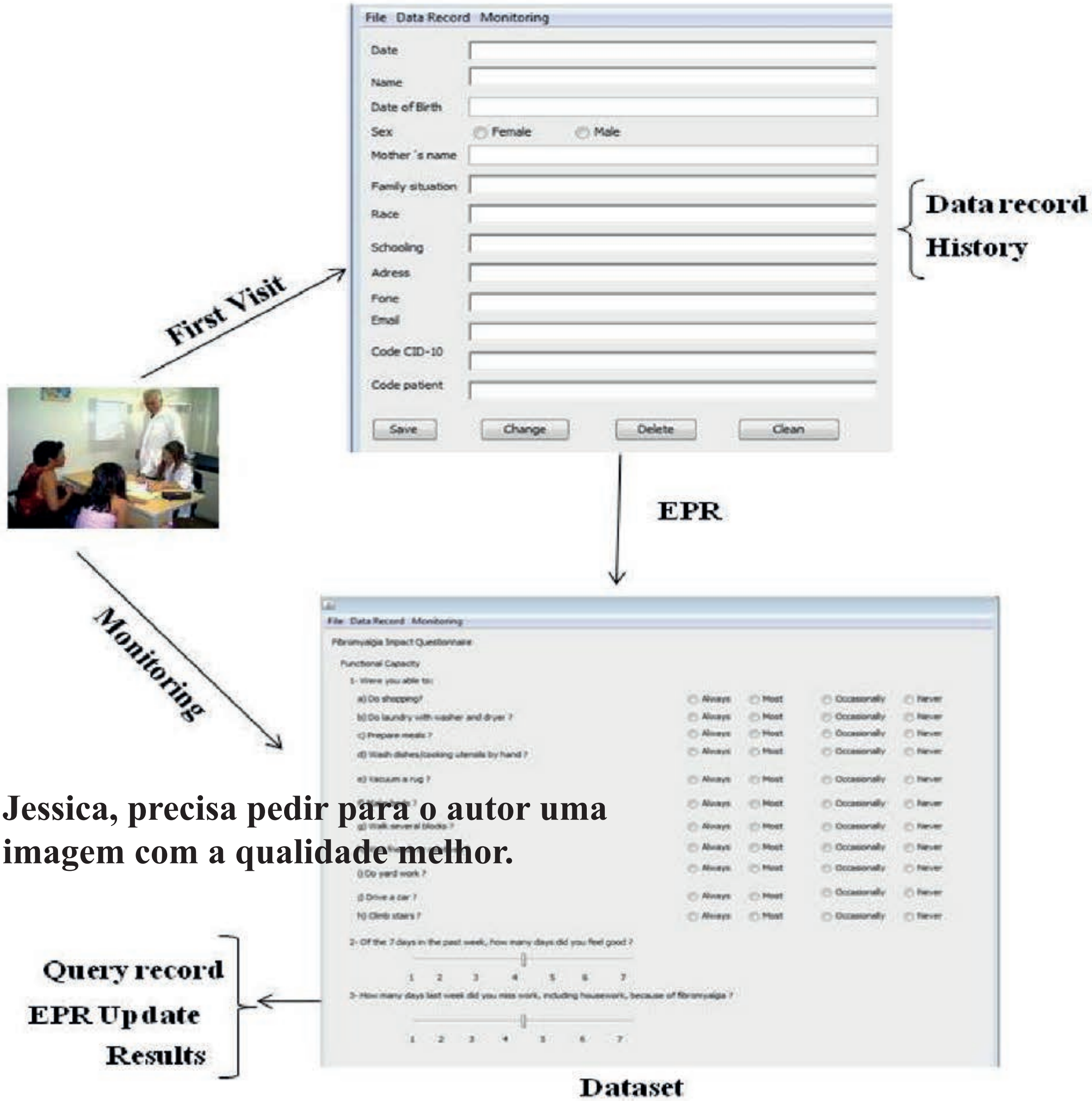
Patients with FMS, in their first contact, are registered in the system using the essential set of minimum data by the PRC. After filling out the information required for registration, the system will generate a login and password for this patient, as shown in Figure 1.

In the first consultation, the patient can be guided and assisted in filling out the information. In the next consultation, these questionnaires will be predetermined by the health professional, and the patient, with the help of the health professional, will log into the system to fill out the form. The time of completion shall be defined by a healthcare professional. When filling out the form, the patient must be accompanied by the professional according to the requirement's specification. In addition, the patient can access the information system anywhere that is connected to the Internet using the login and password.

Once registered, the result may not be modified by a health professional, only viewed.

By accessing the information in SISFIBRO, the professional can assess the results of evaluation methods and can monitor the condition of the patient with FMS, using the chartsto monitor the evolution of the behaviour of the stored data and to think about the therapeutic decision and its efficiency.

The SISFIBRO allows the completion and visualisation of data by different professionals, preventing the



Fibromyalgia Impact Questionnaire

Functional Capacity

1- Were you able to:

a) Do shopping? ○ Always ○ Most ○ Occasionally ○ Never
b) Do laundry with washer and dryer ? ○ Always ○ Most ○ Occasionally ○ Never
c) Prepare meals ? ○ Always ○ Most ○ Occasionally ○ Never
d) Wash dishes/cooking utensils by hand ? ○ Always ○ Most ○ Occasionally ○ Never
e) Vacuum a rug ? ○ Always ○ Most ○ Occasionally ○ Never
f) [illegible] ○ Always ○ Most ○ Occasionally ○ Never
g) Walk several blocks ? ○ Always ○ Most ○ Occasionally ○ Never
[illegible] ○ Always ○ Most ○ Occasionally ○ Never
i) Do yard work ? ○ Always ○ Most ○ Occasionally ○ Never
j) Drive a car ? ○ Always ○ Most ○ Occasionally ○ Never
h) Climb stairs ? ○ Always ○ Most ○ Occasionally ○ Never

2- Of the 7 days in the past week, how many days did you feel good ?

1 2 3 4 5 6 7

3- How many days last week did you miss work, including housework, because of fibromyalgia ?

1 2 3 4 5 6 7

Jessica, precisa pedir para o autor uma imagem com a qualidade melhor.

Figure 1. Patient information registration and filling.

same questionnaires to be answered in a short period of time because usually no changes occur in the condition of the patient. We can give the example of a patient who goes to the rheumatologist, who recommends completing the FIQ and VAS. After the medical assessment, the patient is sent to the physical therapist, who can view the evaluation and monitoring methods completed in the medical consultation and analyse them. In addition to allowing the visualisation of the results of the evaluation and monitoring methods completed by patients in different health services and the sharing of information among professionals, the SISFIBRO also allows the determination of the epidemiological profile of patients for population studies.

Object-oriented modelling of SISFIBRO

The use case diagram of SISFIBRO was modelled with the objective of representing the main features of the system in steps: see patients, diagnose illnesses, treat patients, and order tests. Then, the diagram of classes was built, identifying the classes, their attributes, and their relationships.

The objects diagrams (Figure 2) were drawn from the diagram of classes for modelling instances. This diagram showed the set of objects and their relationships.[8] The diagram provides a view of the values currently stored by the objects while the software is being implemented.

The sequence diagrams (example in Figure 3) describe interactions between objects and show the flow of messages.[9]

Modelling the Entity Relationship Diagram

After the object-oriented modelling of SISFIBRO, we used the mapping of the diagram of classes diagram for the RSD (Figure 4).

Phase II - implementation, data analysis, and SISFIBRO

To examine the functioning of SISFIBRO after its creation, the data were registered.

DISCUSSION

One of the key steps for the specification of SIS

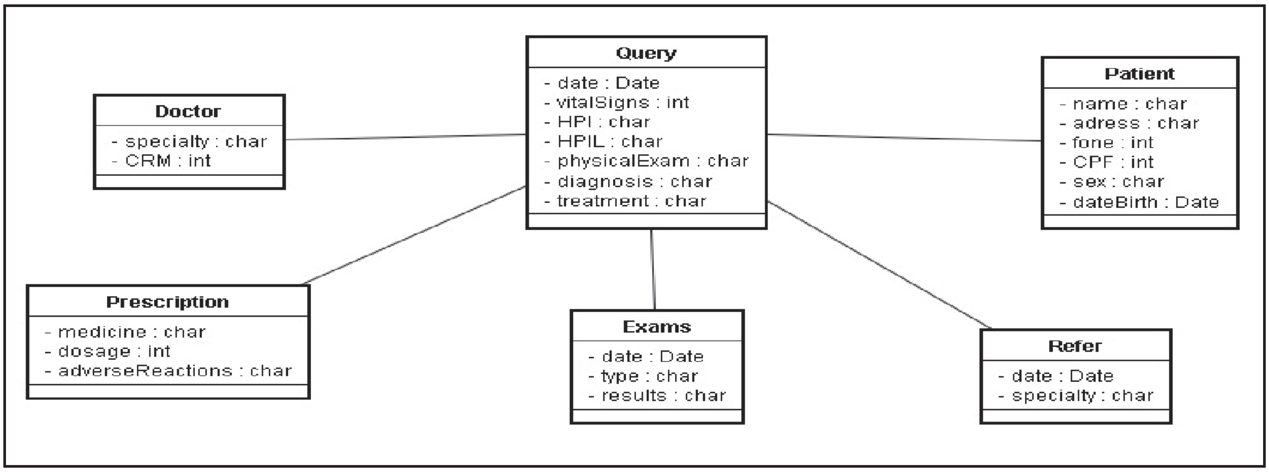


Figure 2. Classes Diagram

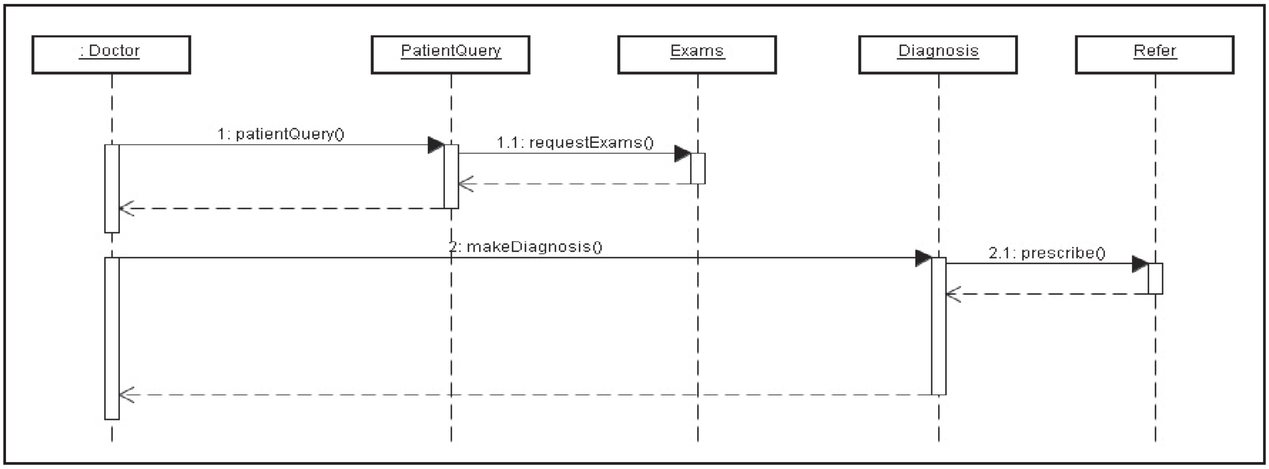


Figure 3. Sequence Diagram.

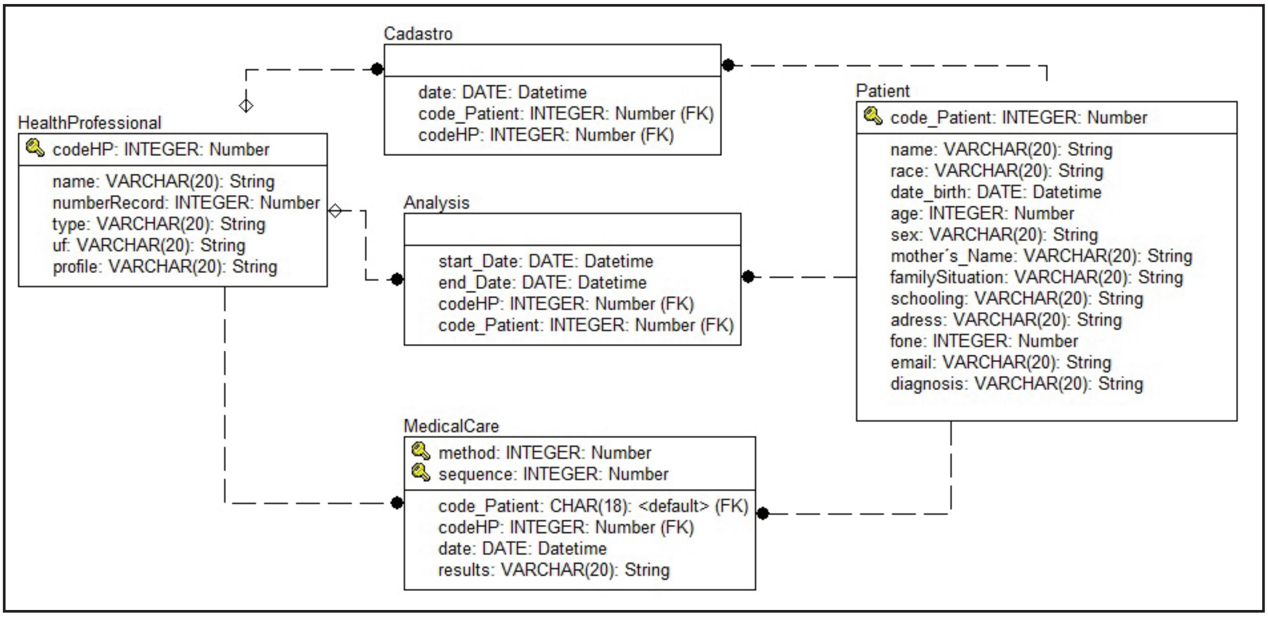


Figure 4. Portion of the RSD related to registration and patient care.

is to identify the data needed for the system, transforming the information found in the real world to the computer world.(10)Because FMS lacks a standardised protocol to collect information and records relating to the care of patients, the data need to be defined before developing the system.

Despite FMS having a standard diagnosis, other conditions are associated with it, such as depression, anxiety, and sleep disorders. These conditions may alter the level of pain of the patients, promoting significant changes in their quality of life. Thus, all of the information relating to the assessment and monitoring of the patients with FMS should be covered by the system.

The methods selected for the SISFIBRO exemplify evaluation methods used in health care such as the use of questionnaires and scales, standardisation, reduced errors, and improved quality of information.(11)

It was important to verify whether the instruments cited in the literature were used by professionals in their clinical practice or whether they were part of routine care. Some instruments may fail due to a lack of participation of users during the design and implementation of the system;(12)this change would hinder the interaction of the users with the proposed system.

Although the number of specialists was not very large, all are linked to educational institutions, and some are researchers who publish articles in the area of FMS, which makes them leaders and influencers of therapeutics. Researchers tend to collect more information in a more systematic way than others, and they could be the potential users of SISFIBRO. In future studies, criteria and information bases that allow the inclusion of more professionals should be used. At a later stage, we intend to perform the validation of SISFIBRO with users in a real situation for improvement and for cultural adaptation. FMS in Brazil is under constant study, and treatment is given in outpatient clinics and in chronic pain clinics. The Hospital das Clinicas of Curitiba (HC) has a specific clinic for FMS, and in the state of Sao Paulo, which also has differentiated services for FMS, there are a large number of professionals, mainly physical therapists. In this type of study, the quality of the professional profile determined the quality of the study more than the number of professionals involved. In an online poll with 16,531 doctors of Barcelona, it was found that the vast majority (61.39%) did not use an automated means for communication and information management in clinical practice. In contrast, the 31.8% who used computerised means constituted an integrated group able to validate and disseminate health information.(13)

The initial idea of SISFIBRO was to unite all of the methods into a single form, facilitating completing the form; however, after a review, it was found that the data were similar but that the understanding and answers changed from one instrument to another. For example, for an item on the Fibromyalgia Impact Questionnaire (FIQ): "How often can you clean the house?",the choices are the following: always, almost always, and once in a while.Whereas for an item on the Questionnaire Quality of life SF-36: "Due to your health, do you have difficulty doing moderate activities such as moving a table, vacuuming, playing ball, sweeping the house?",the choices correspond to the following: yes, very difficult, yes little difficult, or not difficult at all. Thus, it was decided to keep the assessment instruments in their entirety, as they were validated for the Portuguese language.

Despite the Sleep Inventory not showing a significant citation index, it was included in the form because sleep disorders are frequent in FMS and they influence the pain that the patient feels and the patient's functionality.(14) The low use of the sample by health professionals may also be related to the prevalence of physical therapists in relation to rheumatologists.

The evaluation methods of FMS in the literature are often used by health professionals in their clinical practice, except for the McGill Pain Questionnaire, the Inventory of State-Trait Anxiety Inventory, and the Inventory of Sleep. The McGill Pain Questionnaire, aside from being complex and extensive, has been used less in the daily lives of professionals. The lower frequency of the State-Trait Anxiety Inventory can be explained because the survey did not include psychologists and did not have a translation and validation into Portuguese. The Beck Depression Scale, even though it is only permitted to be used by psychologists in Brazil, was included in SISFIBRO because it contained key data for other professionals,resulting in a multidisciplinary approach. An SIS should meet the needs of professionals working directly with patients, including the elements necessary for any area at any time.(11,12)

The completion of the form by the professionals revealed a convergence between the literature and clinical practice of rheumatologists and physical therapists. Other methods of evaluation will be required if areas such as psychiatry, psychology, and neurologyare to be included. Being multidisciplinary, SISFIBRO allows the future inclusion of other instruments because they are modelled using the methodology defined in this work.

Research has shown that these instruments are not often used in clinical practice because they are in the form of paperandrequire a long time to record and analyse the information. "Lack of time" and "impracticality" discourages the use of questionnaires, which shows the need for the information system proposed.

Professions such as nursing already have a standardised method for collecting information corresponding to a systematic and continuous process of planning and management of the patient. This process promotes the standardisation of a set of items that help to identify the health condition of the patient and support making decisions and drawing up a plan of care.(15)

In physical therapy, this standardisation is still incipient. The Program of Technology in Health of the Catholic University of Parana (PPGTS) is preparing studies that seek to establish standards that involve the specification of a set of core data for the electronic health record in physical therapy. One of the studies have been published that have contributed to the widespread use of electronic health records is the Expert System in Manual Therapy. (16) New studies have been published highlighting the work of Buyl and Nyssen(3), which proposes an electronic registration in physical therapy that was prepared in Belgium. This work was based on the International Classification of Functioning (ICF). However, it should be noted that Belgium already has a computerised system of health and that the population is much smaller than that of Brazil.

The literature showed that there wasa growing number of published articles related to FMS and chronic pain in the last ten years; however, it was lacking in relation to information systems.

The absence of an SIS related to the evaluation and monitoring of patients with FMS did not allow a comparative analysis with SISFIBRO. Nevertheless, after the inclusion of patient data, it showed that the specified and implemented system has the necessary functions to record and evaluate information regarding the care of patients with FMS.

SISFIBRO enables integration to PEP, allowing the collection of data directly related to attendance. The amount of data should be kept to a minimum and should include only the essential data to obtain a higherquality ofgenerated information. The SISFIBRO also facilitates the presentation of results to patients by enabling visualisation and by keeping the monitoring simple. The system will allow continuous updating of assessment tools as the state of the art is being updated.

CONCLUSIONS

SISFIBRO enables the clinical evaluation, monitoring, and treatment of patients with FMS as it stores and organises the data needed to conduct these activities, thus helping professionals in their clinical practice.

The use of UML facilitates the integration of new methods of evaluation to SISFIBRO and enables other implementations of the system to beconducted in an intuitive way to facilitate the integration of SISFIBRO with other health information systems.

SISFIBRO is expected to assist health professionals to assess and monitor their patients with FMS and to assist in the provision of appropriate treatment for them.

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