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Development of software for the monitoring of multiple sclerosis

Desenvolvimento de software para o monitoramento da esclerose múltipla

Desarrollo de software para el seguimiento de la esclerosis múltiple

RESUMO

Objetivo: Desenvolver um software para o monitoramento de parâmetros clínicos, indicativos de comprometimento da funcionalidade de indivíduos com Esclerose Múltipla. Método: Trata-se de um estudo metodológico com produção de tecnologia, norteado pelos processos de engenharia de software propostos por Pressman, com base no ciclo de vida de desenvolvimento de sistemas. Resultados: Foram construídas interfaces simples, prototipagem de telas de início, cadastro de profissionais, cadastro de pacientes e cadastro de instrumentos de pesquisa (perguntas, respostas e pontuações). Conclusão: Acredita-se na contribuição do protótipo como uma ferramenta tecnológica capaz de informatizar os dados necessários ao cuidado sistematizado, contudo, o percurso de desenvolvimento é longo e complexo, envolve teste de simulação, avaliação da usabilidade e operabilidade, repetição dos ciclos, realização de novos estudos que retratarão sua utilidade, adequação e melhoramento.

DESCRITORES: Software; Informática Médica; Esclerose Múltipla.

ABSTRACT

Objective: To develop software for monitoring clinical parameters, indicative of impaired functionality in individuals with Multiple Sclerosis. Method: This is a methodological study with technology production, guided by the software engineering processes proposed by Pressman, based on the systems development life cycle. Results: Simple interfaces were built, prototyping of start screens, registration of professionals, registration of patients and registration of research instruments (questions, answers and scores). Conclusion: It is believed that the prototype contributes as a technological tool capable of computerizing the data necessary for systematic care, however, the development path is long and complex, involving simulation testing, usability and operability assessment, repetition of cycles, realization new studies that will portray its usefulness, adequacy and improvement.

DESCRIPTORS: Software; Medical Informatics; Multiple sclerosis

RESUMEN

Objetivo: Desarrollar software para monitorear parámetros clínicos, indicativos de funcionalidad deteriorada en individuos con Esclerosis Múltiple. Método: Se trata de un estudio metodológico con producción de tecnología, guiado por los procesos de ingeniería de software propuestos por Pressman, con base en el ciclo de vida del desarrollo de sistemas. Resultados: Se construyeron interfaces simples, prototipos de pantallas de inicio, registro de profesionales, registro de pacientes y registro de instrumentos de investigación (preguntas, respuestas y puntajes). Conclusión: Se cree que el prototipo aporta como una herramienta tecnológica capaz de informatizar los datos necesarios para la atención sistemática, sin embargo, el camino de desarrollo es largo y complejo, involucrando pruebas de simulación, evaluación de usabilidad y operabilidad, repetición de ciclos, realización de nuevos estudios que retratará su utilidad, adecuación y mejora.

DESCRIPTORES: Software; Informática Médica; Esclerosis múltiple.

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INTRODUCTION

The last few decades, lots of countries have been directing their actions to the innovative technologies incorporation, applied at the field of healthcare, with the purpose of assisting the users and professional' s performance at the care promotion [1], bringing significative changings to the assistential practice, especially in concerning to the diagnosis, treatment and the forms of organisation of the services [2]. The Brazilian reality brings the universal health care "SUS" (Sistema Único de Saúde - Unique Health System) as a important integrant of the technologies, with high investment and continuous incentive to the innovation incorporations of technologie' s breakthroughs by their managers at many instances [3,4,5].

In spite of the relevance in the use of informatics at the field of health, many are the challenges to the desenvolver and applicability of new technologies at the various levels of assistance, with an emphasis to the needed acquisitions resources limitations, regarding to machines, softwares and human resources [4]. However, those challenges may be mitigated when the systems are elaborated with the participation of professionals with expertise at the software' s application area, in a way to build a support's system at the assistential practice, minimizing biases [5].

In what concerns the Multiple Sclerosis (SM), it is a chronic disease, degenerative, autoimmune, who's comprises the Central Neural System and generates alterations at the individual' s organic functionality, promoting incapacities and limitations. The disease affects, most of the time, the group of people between 18 and 55 years old [6], although this condition can be found out of this age group.

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It must point out that those challenges are experienced by the multiprofessional team whom compose the Diagnosis and Treatment of the Multiple Sclerosis Treatment Reference centers, majorly in what concerns the disease' s clinical variation manifestations, bringing to light the need of developing a software that helps the health multidisciplinary team at the patient's clinical and epidemiological profile acknowledge, at monitoring the disease, identifying adverse events related to the medical therapy and consequently at the decision making over the patient's health needs, encouraging the implantation of a new technology whos permit planning, agility and priority in the actions.

There is a gap in what concerns the Brazilian softwares that monitors the disease. There are no reports, in Brazil, about the software development related to the SM, however those might be identified in other countries, as well as England with the DAWN MS Multiple Sclerosis Software, which efficiently monitors the health and urine exams of patients with disease modifying therapy [7]. The study had the goal of developing a software that allows the EM's tracking, and that can be used by professionals of the specialized interdisciplinar pro-

fessionals and by monitoring individuals at the Reference Centers, in a way to contribute to the quality of the assistance and developing of future researches.

METHOD

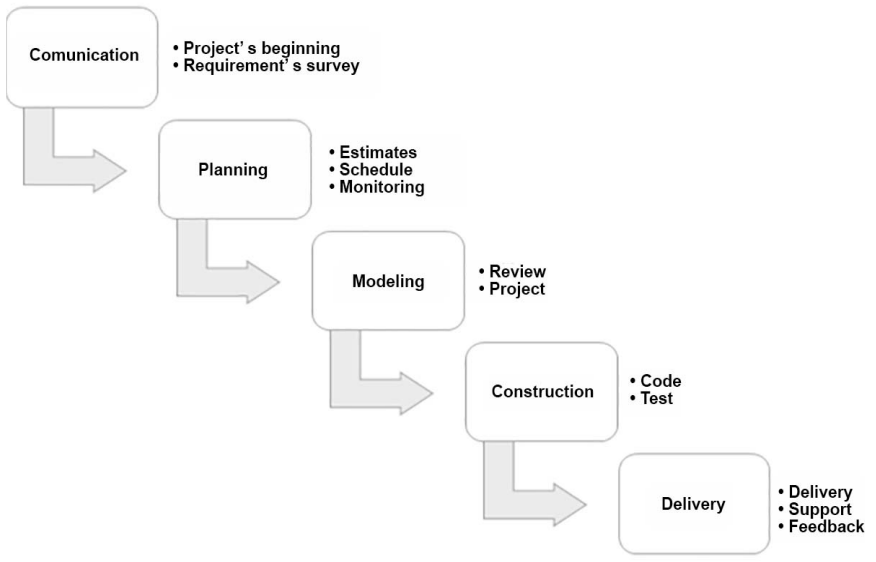
It is about applied and methodological research, in which an developing of a software was made, MSCARE (Care in Multiple Sclerosis), to be applied in a Multiple Sclerosis Reference Center in João Pessoa - PB (Brasil). For that matter, it relied on 241 medical records of individuals registered at the Multiple Sclerosis Reference Center. Of that amount, 50 were selected by non probabilistic sampling. The registered and selected users have made use of a first and second line medicamental therapy, according to the Health Ministry Clinical Protocol and Therapeutic Guidelines to Multiple Sclerosis Treatment [6].

The methodological path to the software' s development was guided by his engineering processes, proposed by Pressman, according to the "waterfall" prescriptive process model, whose concern is to estructurate and ordinate the software's development (Image 1) [8].

For the software' s developing a communication with the Multiple Sclerosis Reference Center (CREM) professionals was demanded, and the professional with expertise in system developing, through systematic reunions, where the software' s requirements were discuss, such as the form of usuaries registering, their access to the system, the clinical and epidemiological variation presentation, comprising the first processes stage. In the following steps, a planning of the software' s project was made, regarding a schedule and the monitoring of activities to be done at the prototype building.

After accomplishing those tasks, the instrument 's conversion of the data collection and clinical information was made. The screen 's interface was structured, inicialy in the paper, followed by the software Balsamiq Mockups (tool for the design prototype creation) usage. The software was built using a programing language (Hypertext

Image 1 - Life's cycle at the "waterfall model":



Source: PRESSMAN; MAXIN (2016) (8).

Processor), A general using script open source' s language, specially suited for the web' s plataform desenvolving. For that purpose, a Framework PHP (Laravel 5.2 Open Source) was used and the My SQL as data bank tecnologie. For screen's developing, other programs were used, as well as HTML5, CSS3 and JQUERY, resulting in the MSCARE' s softwares.

At the following step, the tools who would contribute to the prototype modeling, diagrams elaboration and programming language definition were set out. A UML' s diagram (Unified Modeling Language) was developed with the assistance of the JUDE' s System Design Tool (tool for UML support system modeling). At the fourth step of the "waterfall" accomplishment, the software's prototype was provided to the main research, through the system' s installation in a local testing server, promoting a controlled testing environment. To the "MSCARE" sunctionning, thereby, were used the following programs: Apache, PHP and MySQL, beginning in that way, the tests phase, with the insertion of the data at the system.

During the test phase, a number of adjusting needs in its functionality, agility in data insertion, amendment at the data inclusion were found, as well as at the execution of a few filters who permit the registered patient' s profile characteristics to be visualised, whose registered by sex, age group, etc. Thus, the MSCARE prototype development has arrived to the building stage, however, it aims to advance to the delivery stage, with the system' s access through the web, in a way to ensure an easy access, featuring the advantage of working in many operational systems, be that a landline or mobile technologie and the server, through internet connection. The study has accomplished the ethical norms established by the nº 466/2012 resolution of the National Health council and it's registered at the National System of Ethical Information in Researches Involving Human Beings (SISNEP) with CAAE nº 53877216.8.0000.5188.

RESULTS AND DISCUSSION

The technological tool' s usage at the health services may give support to the professionals in the ambit of decision making in a direct or indirect way. The Information systems and the prontuary management represent the direct form. The systems planned to help in the diagnosis, treatments

and prognostic profiles, who's application minimizes the mistakes and increases the patient' s security, are framed at the direct form of the decision making help [9].

The "MSCARE" software prototype was developed through the union of the programming logic and the Clinical Protocol of the Multiple Sclerosis Therapeutic Health Ministry Guidelines. In this process, defining which fonctions the searcher expected of the software was considered a main question. For that, was determined with the programmer, the order of activities that the systems should execute, considering the ways for users registrement (patients and professionals) and for the registering of researching questionnaires.

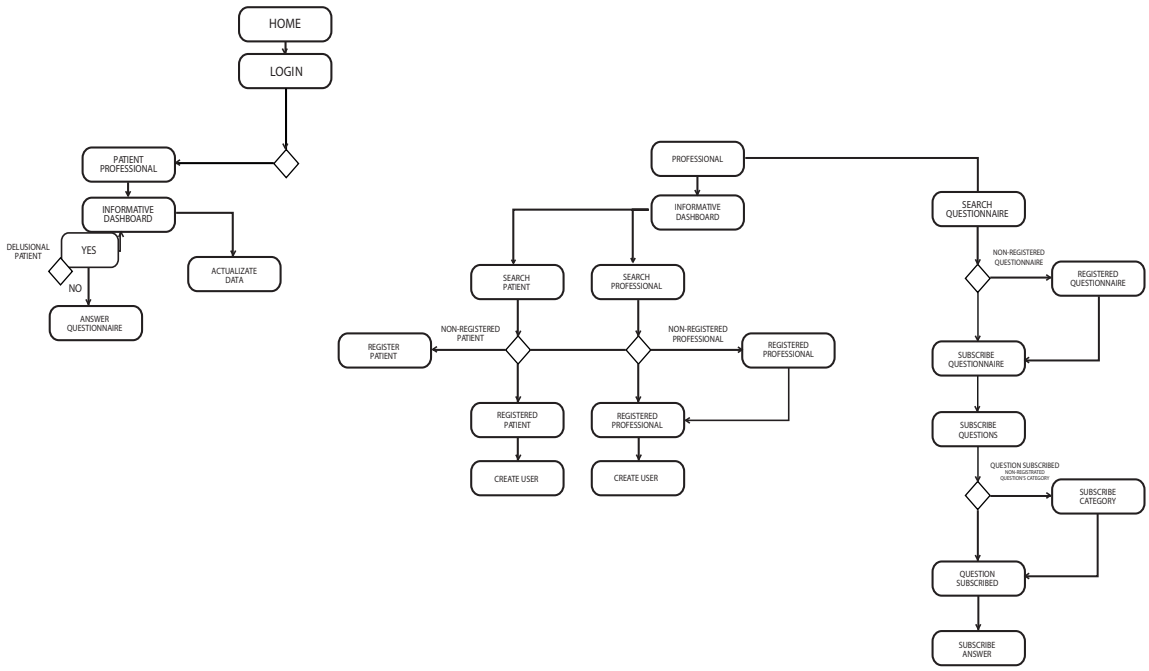
A graphic which shows the course made at the software, as well as directing the programming algorithm developing, was structured, responsible for the computational logic world's connection with the real world. For that matter, a amount of flowcharts at the UML (Unified Modeling Language) language were built. At the flowchart, the connections between the events are represented by lines with arrows to indicate the order or the direction in which the events happen. Those events, represented by the rectangles, for their time refer to the selection of an activity or action, as can be visualised in image 2.

With the aim of making its use easier, simple interfaces were built, which forward the quality of the register of the patients monitored by the CREM, with the Balsamiq Mockups software help. The software 's prototype, MSCARE is constituted of login for the health professional, patients register, searching filters for the registered patients and a place for search insertion [6]. Its emphasized that the prototype was programmed in a way to possibilite changings in registering data, making it possible to include new informations or adapting those who's already there. In that way, with the aim to increase MSCARE's structure of comprehension, figures 3 and 4 show the patient's register and storage of data gathering.

At the fourth image it is possible to observe the identification data of the registered user (patient), making the options of variations upgrade checking possible, who's important to monitoring of the Multiple Sclerosis cases, fully necessary to the disease progression monitoring, in what concerns to EDSS (Kurtzke's scale of expanded incapacity state) which must be annually upgraded. Beyond that, the saving button must be emphasized: it may be actioned after the data insertion and in wrong registering insertion, the system also permits the information's exclusion [8].

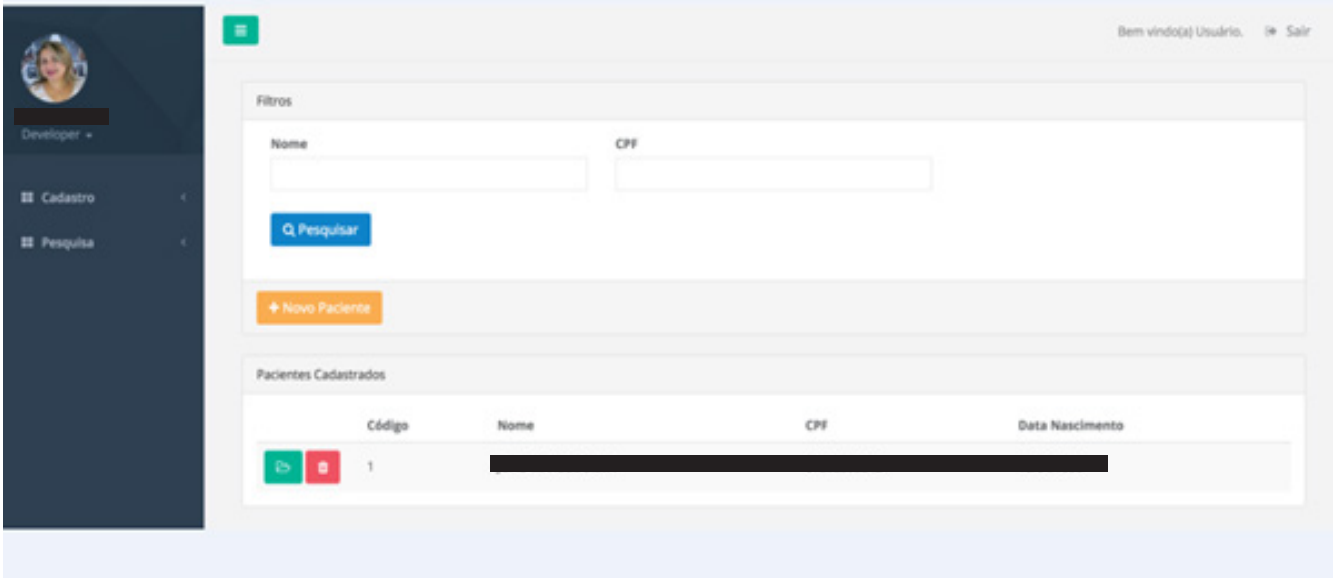
In that way, it is pertinent emphasize that the system has three types of users: the administer who have the function of register the health professional, the health professional who's responsible for the patients electronic subscribing assisted at CREM, filling of the research instruments, relatories generation and the patient user, who,

Image 2 – flowchart of software's functioning - João Pessoa, PB:



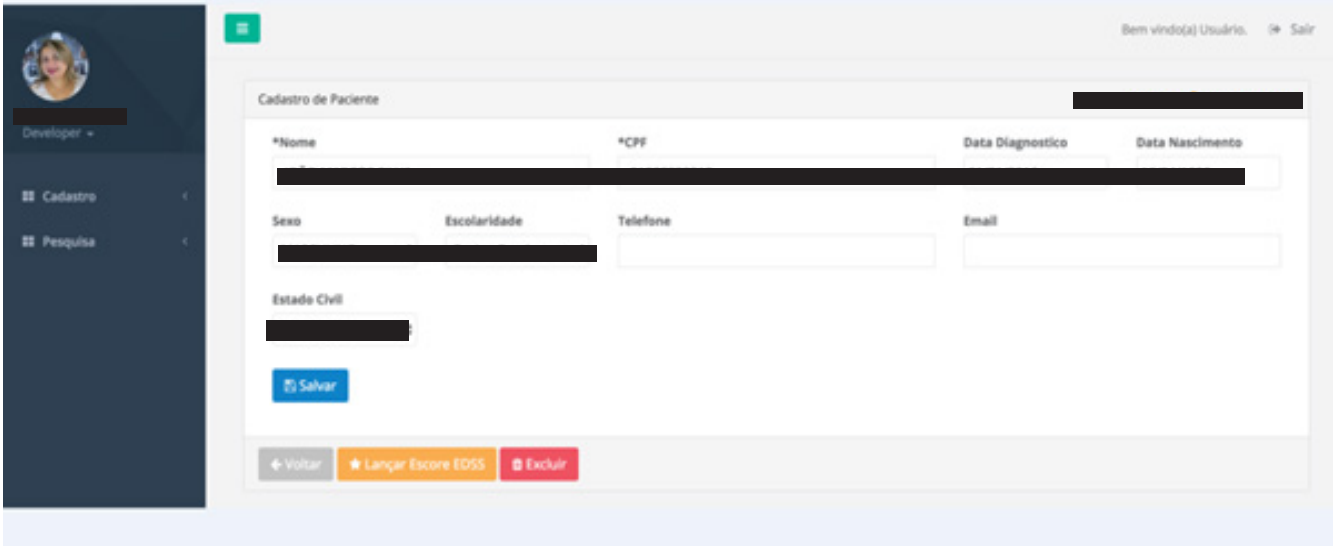
Source: Search data, 2018.

Figura 3 – Interface principal do Interface de cadastro de pacientes do software MSCARE, João Pessoa - PB



Fonte: Dados da pesquisa, 2018.

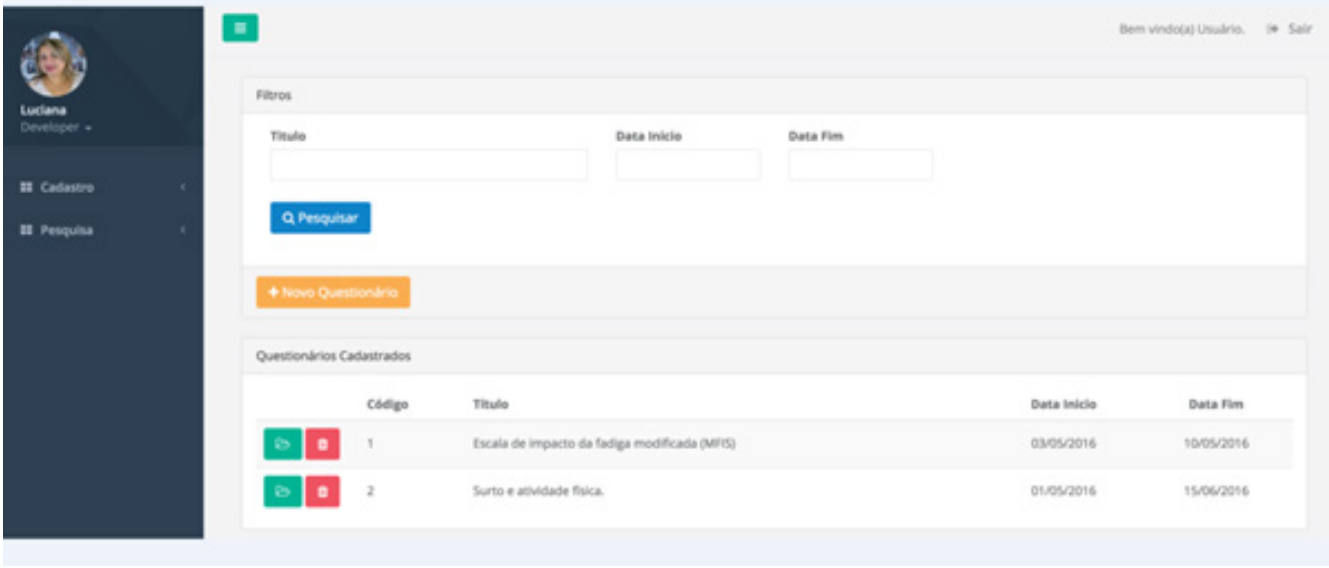
Figura 4 – Interface de cadastro ou de acesso aos Cadastro de Pacientes do protótipo de software MSCARE, demonstração de dados armazenados, João Pessoa-PB:



Fonte: Dados da pesquisa, 2018.

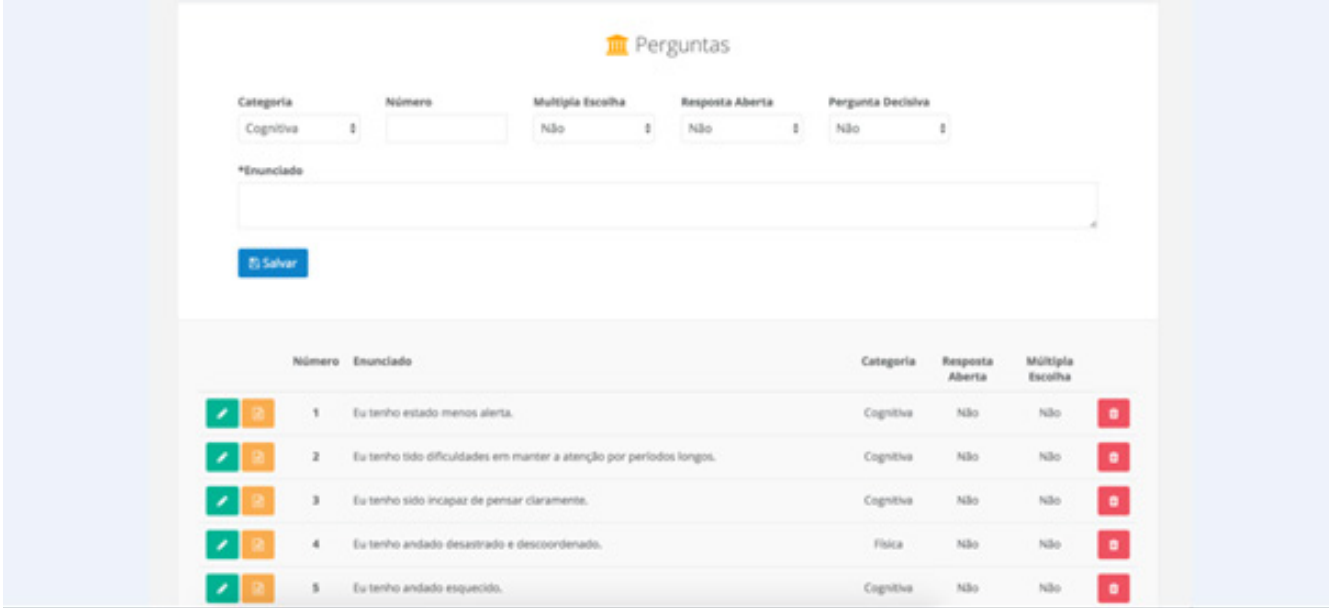
after the registering, can access the system to answer the searching instruments. The interface represented by image 5 presents the purpose of the MSCARE software prototype directed to registering research. The system permits the insertion of diverses modalities of research instruments, making the differentiation of categories or domines possible, as well as of the open or discursives answer register, and closed, with options of one or multiple choice. e fechadas, com opção de uma ou múltipla escolha. Moreover,

Figura 5 - Interface Cadastro de Pesquisa do protótipo de software MSCARE, demonstração de dados armazenados, João Pessoa-PB



Fonte: Dados da pesquisa, 2018.

Figura 6 - Interface Cadastro de Pesquisa do protótipo de software MSCARE, demonstração do registro de perguntas do questionário, João Pessoa – PB:



Fonte: Dados da pesquisa, 2018.

it determines the time in which the instrument will be available for the user (patient) to answer, proportioning the systemization and the periodicity of the accompanying[9].

Before the prototype purpose, the registered research questionaries at the system (image 6), permit the question discrimination according to the categorie to whom belong: multiple choice, open answer or decisive question (yes or no).

At the image 7, it is possible to observe the answers registering option and their respectives punctuation, where the software his own make the mathematical operation and offers the result accordingly to the searching instrument, providing the score of which individual[4].

Other interfaces will be disponible to

Figura 7 - Demonstração do registro das respostas do questionário com as devidas pontuações, João Pessoa-PB:

Fonte: Dados da pesquisa, 2018.

the system users (adm and professionals health), in the example of those who allow generate relatories to the varieties whose correspond to the EM clinical evolution verifications, with the future pretension of a index built, whose from the application of a decision model, came to promote the assistance prioritizing and the major agility at the interdisciplinary decision making, as well as prioritizing the multiprofessional assistance, changing at medicamental therapy, management of the adverses events, etc[6]. It's important to emphasize that in the test' s stage, they were accomplished with the admin user and health team professional, in that way, the test with the patient's users is still in processing and analysis[9].

In this context, this research makes it clear that information systems are important tools in the decision process, as they provide knowledge through the interpretation of collected information, in addition to enabling the adequacy of the planning of health care actions and, consequently, the elaboration of strategies focused on solving the problems encountered [10].

CONCLUSION

The "MSCARE" software prototype has promoted the agility and quality of the information, in a way to possibilite the future application of a decision model, that results at the action planning base in scientific evidence, that provides results related to the assistance priority, searching for a care's quality increase.

It is worth to saliantate that a new technology desenvolviment, based at theintegration between the professionals and the patients, implies at a information production who will be transformed in acqknowledge, constituting a differential at the interdisciplinary team decisions making upon the challenge facing, experienced at the MS care, especially in what concerns to the individualized assistance needs. The prototypes contribute as a technological tool capable of automating necessary data to systematized care becomes evident; the development course is, however, long and complex.

REFERENCES

1. J. Glenn Brookshear, JG, Piveta, EK. Ciência da Computação: Uma Visão Abrangente. [cited 2018 mai 16] 11.ed. São Paulo: Bookman, 2013.

2. Baptista PCP, Felli VEA, Mininel VA, Karino ME, Silva SM, Tito RS, Peduzzi M, Sarquis LMM. A inovação tecnológica como ferramenta para monitoramento da saúde dos trabalhadores de enfermagem. Rev Esc Enferm USP. [Internet] [cited 05 mar 2016]; 1621-6, 2011. Available from: http://www.scielo.br/reeusp.

3. Silva HP, Petramale CA, Elias FTS. Avanços e desafios da Política Nacional de Gestão de Tecnologias em Saúde. Rev Saúde Pública. [internet] 46 (supl): 83-90, 2012. . [cited 2018 mai 12]. Available from: https://www.scielo.br/pdf/rsp/v46s1/co4220.pdf.

4. Matsuda LM, Évora YDM, Higarashi IH, Gabriel CS, Inoue KC (2015). Informática em enfermagem: desvendando o uso do computador por enfermeiros. Texto Contexto Enferm. [Internet] Florianópolis. Jan-mar; 24(1): 178-86. 2015. [cited 05 mai 2016]; Available from: https://www.scielo.br/pdf/tce/v24n1/pt_0104-0707-tce-24-01-00178.pdf.

5. Silva KL, Évora YDM, Cintra CSJ. Desenvolvimento de software para apoiar a tomada de decisão na seleção de diagnósticos e intervenções de enfermagem para crianças e adolescentes. Rev. Latino-Am. [internet] Enfermagem set-out. 23(5):927-35, 2015. [cited 02 mai 2016]. Available from: https://www.revistas.usp.br/rlae/article/view/106163.

6. Brasil. Ministério da Saúde. Secretaria de Atenção à Saúde.

REFERENCES

Portaria Nº391 de 5 de maio de 2015, aprova o Protocolo Clínico e Diretrizes Terapêuticas da Esclerose Múltipla. Brasília, DF: Ministério da Saúde. 2015. [cited 08 mai 2016]. Available from: https://antigo.saude.gov.br/images/pdf/2019/outubro/10/PCDT-Esclerose-M--ltipla.pdf.

7. Dawn Software. Keep your DMT Patients Safe. 2019. [cited 02 mai 2016]. Available from: http://www.4s-dawn.com/wp-content/uploads/2016/08/DAWN-MS-Brochure.pdf

8. Pressman, Roger S, Maxim, Bruce R. Engenharia de software: uma abordagem profissional. 8 ed. Porto Alegre: AMGH, 2016. [cited 31 mai 2016].

9. Lopes SP, et al. Desenvolvimento de protótipo de software para auxílio na aplicação de indicadores de qualidade em terapia nutricional. Journal of Health Informatics. [internet] Julho-Setembro. v 7(3). p 75-81. 2015 [cited 25 mai 2016]. Available from: http://www.jhi-sbis.saude.ws/ojs-jhi/index.php/jhi-sbis/article/view/341.

10. Holmes ES, et al. Health Information Systems in the Decision-Making Process in Primary Care. International Archives of Medicine Section: Global Health & Health Policy. 9(2). 2016. [cited 25 mai 2016]. Available from: www.intarchmed.com and www.medbrary.com.