

ESSENTIAL DATA SET'S ARCHETYPES FOR NURSING CARE OF ENDOMETRIOSIS PATIENTS

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ABSTRACT

This study aimed to develop an Essential Data Set for Nursing Care of Patients with Endometriosis (CDEEPE), represented by archetypes. An exploratory applied research with specialists' participation that was carried out at Health Informatics Laboratory of PUCPR, between February and November of 2010. It was divided in two stages: CDEEPE construction and evaluation including Nursing Process phases and Basic Human Needs, and archetypes development based on this data set. CDEEPE was evaluated by doctors and nurses with 95.9% of consensus and containing 51 data items. The archetype "Perception of Organs and Senses" was created to represent this data set. This study allowed identifying important information for nursing practices contributing to computerization and application of nursing process during care. The CDEEPE was the basis for archetype creation, that will make possible structured, organized, efficient, interoperable, and semantics records.

Descriptors: Data collection. Nursing records. Nursing informatics. Information systems. Endometriosis.

RESUMO

Objetivou-se elaborar um Conjunto de Dados Essenciais de Enfermagem para Atendimento às Portadoras de Endometriose (CDEEPE) e representá-lo por arquétipos. Pesquisa exploratória, aplicada com participação de especialistas, realizada no Laboratório de Informática em Saúde da PUCPR, entre fevereiro e novembro de 2010. Foi dividida em duas etapas: construção e avaliação do CDEEPE, que abordou as fases do Processo de Enfermagem e as Necessidades Humanas Básicas; e desenvolvimento dos arquétipos, a partir do conjunto definido. O CDEEPE foi avaliado, por médicos e enfermeiros, com média consensual de 95,9% e foi especificado contendo 51 dados. Para representá-lo, foi criado o arquétipo "Percepção dos Órgãos e Sentidos". Este estudo possibilitou identificar informações importantes para a prática de enfermagem, contribuindo para informatização e aplicação do Processo de Enfermagem no cuidado prestado. O CDEEPE foi base para criação do arquétipo, que possibilitará os registros de forma estruturada, organizada, eficiente, interoperável e semântica.

Descritores: Coleta de dados. Registros de enfermagem. Informática em enfermagem. Sistemas de informação. Endometriose.

Título: Arquétipos do conjunto de dados essenciais de enfermagem para atendimento de portadoras de endometriose

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RESUMEN

El objetivo era desarrollar un conjunto mínimo de datos esenciales para la atención de enfermería de pacientes con endometriosis (CDEEPE,) y lo representa por arquetipos. Investigación exploratoria aplicada con la participación de especialistas que se llevó a cabo en el Laboratorio de Informática de la Salud de PUCPR entre febrero y noviembre de 2010. Estaba dividido en dos etapas: construcción y evaluación del CDEEPE, incluyendo las fases del proceso de enfermería y las necesidades humanas básicas y el desarrollo de los arquetipos basados en el conjunto de datos definido. El CDEEPE fue evaluado por los médicos y enfermeras con un promedio de consenso del 95,9% y se especificó con 51 elementos de datos. El arquetipo de "Percepción de órganos y los sentidos" fue creado para representar este conjunto de datos. Este estudio permitió identificar la información importante para las prácticas de enfermería contribuyen a la informatización y la aplicación del proceso de enfermería durante la atención. El CDEEPE fue la base para la creación de arquetipo, que hará posibles los registros estructurado, organizado, eficiente, interoperable y semántico.

Descriptor: *Recolección de datos. Registros de enfermería. Informática aplicada a la enfermería. Sistemas de información. Endometriosis.*

Título: *Arquetipos de datos clave para la atención de enfermería de pacientes con endometriosis.*

INTRODUCTION

The use of data collection instruments that characterize the nursing care based on a critical thinking, operating on the health-disease process in a systematic way, contributes to the improvement of the quality on the treatment, besides it favors the decision taking⁽¹⁾. However, it is essential that this instrument contains a data collection based on the International Nursing Minimum Data Set (i-NMDS) patterns⁽²⁾ and use, as scientific basis, the theoretical tools "Basic Human Needs" by Wanda A. Horta⁽³⁾ and the nursing process⁽⁴⁾.

The adoption of a data set is facilitated by the use of computerized systems and its success depends on well specified data⁽⁵⁻⁶⁾. Besides that, for the Electronic Health Records (EHR) to be structured and organized efficiently it is essential they are based on health field patterns, such as the archetypes representation, proposed by OpenEHR Foundation⁽⁷⁾. This pattern defines the specification and the semantic representation way of the clinical data to EHR, enabling the interoperability between systems⁽⁷⁻⁸⁾. In 2011, Brazilian Ministry of Health stated in the Ordinance No. 2073 (DOU 169, September 1st, 2011) the archetypes as pattern of interoperability and information in health for the EHR.

A well defined data set and its representation on archetypes favors the standardization of information systems in nursing, contributing positively on treatment. Considering that there are diverse clinical diagnoses that suffer with lack of systematized information, it is fundamental that data set

referring to that treatment be structured, including the nursing approach.

Endometriosis is one of these diagnoses, and it deserves special attention for being a gynecological affection that reaches around 10-15% of women on reproductive age all over the world. Such clinical picture has high prevalence, uncertain etiopathogenesis, chronicity and morbidity. Because of its characteristics and comprehensiveness, in 2006, Brazilian Ministry on Health established the clinical protocol and therapeutic guidelines to *endometriosis* treatment, which was revised and updated in 2010 by the Ordinance SAS/MS No 144⁽¹⁰⁾.

Considering that endometriosis is difficult to diagnose, nurses play a significant role in facilitating this task, performing an evaluation and an adequate screening, besides providing education, orientation and support, helping to alleviate the consequences that endometriosis can bring to patients. It can be done by playing an important role on holistic care, by the preoperative period and by an understanding on the these women's daily life⁽¹¹⁻¹²⁾. So, the guiding question to this work is: what information is essential for the creation of a data set in medical records, leading nursing records during these treatments?

The aim of the formal study was developing a set of essential nursing data to the women health medical records, related to the treatment of those with endometriosis, and represent it by archetypes. Such data set is going to be used in an EHR, requirements for a system that uses it were also specified.

METHOD

Exploratory research with experts participation, developed in the Laboratory of Informatics in Health of Pontifical Catholic University of Paraná (Laboratório de Informática em Saúde da Pontifícia Universidade Católica do Paraná – PUCPR), in Brazil, during the period of February to November, 2010. This study was approved by the Ethics in Research Committee from PUCPR by the document No 0004117/10.

The study was divided in two stages: the qualitative analysis on data identification (Stage I) and the EHR requirements (Stage II); quantitative analysis on data selection, which composes the proposed set (Stage I).

Stage 1 – Construction and evaluation of “Essential Data Set for Nursing Care of Patients with Endometriosis” (CDEEPE)

The CDEEPE was based on the theoretical analytical referential: Categories of Patient Demographics Data and Data on the Nursing Care of the Minimum Data Set of Nursing^(2,6); conceptual model by Wanda Horta about the Human Basic Needs⁽³⁾; in the five phases of the Nursing Process defined by Cofen Resolution No 358/2009: Nursing History and Physical Examination, Nursing Diagnoses, Planning, Implementation and Results and Evaluation⁽⁴⁾, and complemented by other references that had information about the health-disease condition of women with endometrioses, important to the set formations.

Two categories were used for the CDEEPE elaboration, all specified by the International Set of Minimum Nursing data: demographics data that contain general information identifying the patient; and data on nursing care that contain the Form of General Evaluation with Previous History, Health Conditions, Medicines, Nutritional, Physical and Psychological Condition, as well as information to the Nursing Process with Nursing History and Physical Examination (Perceptions and expectations related to the endometriosis, Psychospiritual needs, psychosocial needs, Psychobiological needs); Nursing Diagnoses NANDA I⁽¹³⁾ e CIPETM/CIPESCTM (International Classification to Nursing Practice/ International Classification to Nursing Practice in Collective Health)⁽¹⁴⁾; Nursing Interventions; Nursing Prescriptions, Nursing Evolution and Nursing Results.

CDEEPE was valued by doctors and nurses experts aiming a multidisciplinary approach. These participants identification was done through Internet searching in Centers of Research and Clinics that treated women with endometriosis, using the keywords: “Center of Expertise on Endometriosis in Brazil”, “Center of Endometriosis” and “Endometriosis Clinic”, and for issue on Lattes Platform with the keywords: “Endometriosis”, “Nursing, Woman Health and Endometriosis” and “Endometriosis and Nursing”. All the selected professionals had their curriculum registered on Lattes Platform.

During the selection period, 48 experts were identified (26 doctors and 22 nurses) in Brazil and invited by an e-mail to participate of this research. It was not defined a sample, considering that there are few experts available and that the absenteeism rate in this kind of research is generally high. So, we intended to have the cooperation of as many participants as possible.

The invited gynecologists had worked with endometriosis for at least five years. The selected nurses worked with endometriosis and/or were experts in women health, and had to have experience in women health for at least five years. Among professionals, those with Master degree were included, preferably those with published scientific articles and other works in the endometriosis field.

Six doctors and two nurses accepted to participate in the research, representing 16,6% of the total, who signed and sent an informed consent form by e-mail. Evaluation was made by two independent questionnaires, each one produced to a specific kind of professional and available in the Internet. Each participant had access to his/hers own questionnaire only, it had questions related to Professional Profile and to General Evaluation data, contemplating Previous History; Health Conditions; Medicines; Nutritional, Physical and Psychological State.

Nurses' questionnaire was produced according to the Nursing Process, holding 52 items related to data that had composed CDEEPE, and six items to clarify the nursing activity in relation to women with endometriosis. The doctor's questionnaire had 41 questions related to the information used during treatment and collected by the nurses.

In order to answer each question, the participants judged the degree of importance of

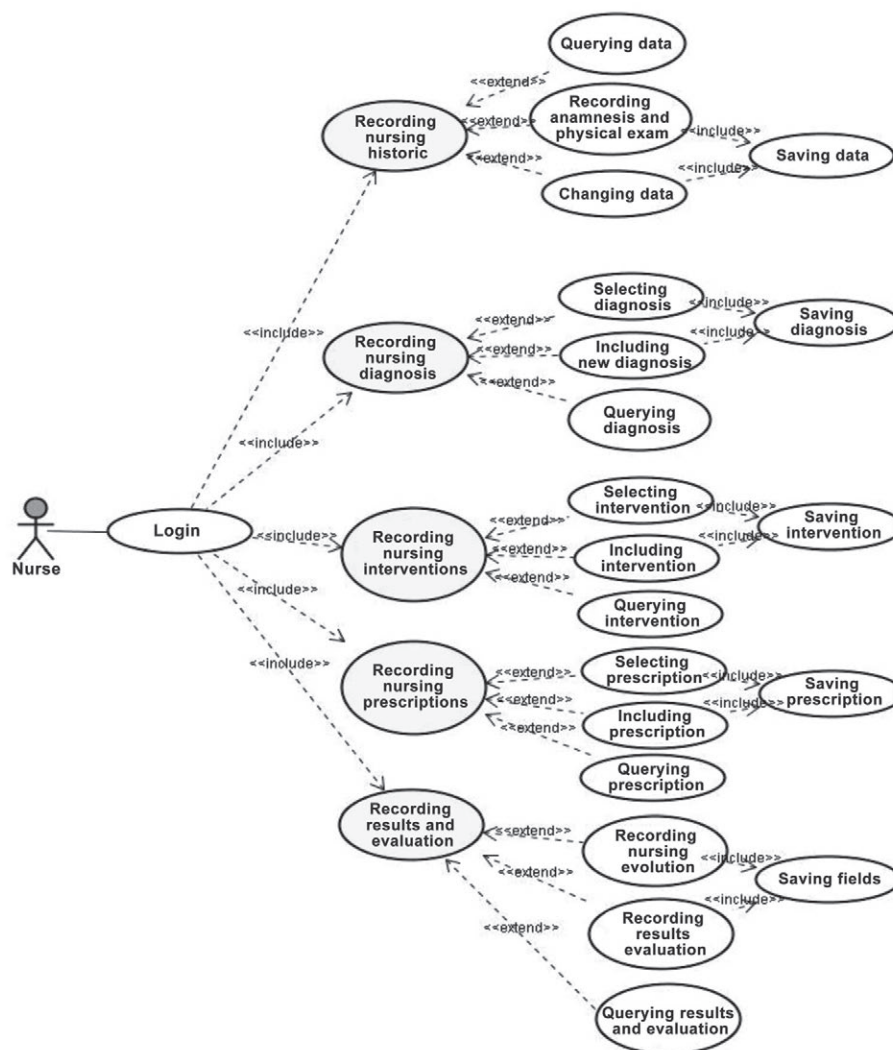
the evaluated data, according to the Likert scale, selecting a value in a scale from 1 to 5: degree 5 (extreme importance), degree 4 (very important), degree 3 (important), degree 2 (little importance) and degree 1 (not important). Hereafter, the importance degree averages of each data were calculated (sum of the degrees defined for each participant divided by the number of answers). Only data presenting an equal average or greater than 60% of importance (greater or equal to degree 3) composes CDEEPE.

Descriptive Statistics was applied in only one "round", because there was no divergence between answers related to the clinical data which could influence the treatment of women with endometriosis.

Stage 2 – Development of the archetype

EHR requirements to the treatment of women with endometriosis were identified based on CDEEPE policies, reasoned on the functionalities and needs of the system to nursing care, based on Nursing Processes. Three use cases diagrams were produced, all according to the oriented analysis to objects, due to the pattern UML (*Unified Modeling Language*): use cases interaction diagram for professionals to EHR; use cases diagram with nursing care to patients, and use cases diagram on nursing treatment to women with endometriosis records (Picture 1).

Regarding use cases diagrams constructions, there were used major functionalities of the system,



Picture 1 – Use cases diagrams on nursing treatment to women with endometriosis. Curitiba, PR, Brazil, 2011.

which correspond to actions that the system and its respective actors (Nurses and Health Professionals) are going to perform.

Required specifications of the use cases were presented in a clear and simple way in order to ease up the treatment during data records performance and to achieve the goal of reaching an adequate nursing treatment. They also represented the interaction between user and system, which means, functionalities of each use case. These processes are important to the development of archetypes that fulfill user needs.

Hereafter, a model was developed based on the structure of archetypes, using the editor of archetypes LinkEHR-ED⁽⁷⁾. The model represents global characteristics of EHR components, how they are aggregated, and the referred context of information to gather the ethical, legal and originality requirements. It defines several generic classes, including the most important, those described in the International Standard Organization (ISO 13606 part 3)⁽⁷⁾: EHR_EXTRACT – the electronic health records of a person; FOLDER – organization of information into folders of an electronic health record; COMPOSITION – section of clinical care, appointment or document; SECTIONS – clinical titles reflecting the workflow or consulting process; ENTRY – clinical statements about “observations”, “evaluations” etc.; CLUSTER – structures of complex data composed of multiple parts; ELEMENT – last structure level, in which data values are placed. Throughout the current study, we chose to use “Cluster” structures composed by its respective elements in the last level, with important data and values.

In order to complement it, three screens corresponding to the system interface were prepared, which means telling, how data filling could work in an HER, according to Basic Human Needs.

RESULTS

CDEEPE results were composed by 51 items, structured as follows:

- Nursing History and Physical Examination: Identification – Item 1 to 12 (Picture 1);
- Perceptions and expectations related to endometriosis – Item 13 to 22 (picture 1);
- Psychospiritual needs – item 23 to 24;
- Psychosocial needs – Item 25 to 30;

- Psychobiological needs – Item 31 to 42;
- Problems Stocktaking – Item 43 to 44;
- Nursing Diagnoses (Item 45):
- Nursing Diagnoses NANDA I 2009-2011 – Item 45.1;
- Nursing Diagnoses CIPE™/CIPESC™ – Item 45.2;
- Nursing Interventions – Item 46;
- Nursing prescriptions – Item 47;
- Nursing evaluation – Item 48;
- Nursing Results – Item 49;
- Evaluation of nursing results – Item 50;
- Identification of the nurse, Number of COREN – Regional Nursing Council (Conselho Regional de Enfermagem) – Item 51.

Picture 2 presents items 1 to 22 which set part of CDEEPE. The complete set is available for free access on the link: https://docs.google.com/viewer?a=v&pid=explorer&chrome=true&srcid=0B6nvE_wCmxYcNDYxZmMxZGUtZGVhZC00MDdhLWFMnDQ0tNmMxZTRlOWVmYjQw&hl=pt_BR

CDEPPE valued by the collaborator doctors and nurses got a consensus with an average of 95.9% on answers “important”, predominating important and very important, with scores averages ranging from 3 to 4.9.

The profile of the professionals who took part in this research demonstrated that they were able to contribute, in a real sense, to CDEPPE formation. Two post-doctors were included in the professionals' group, three doctors and a master student on the field of gynecology and/or women health. Among them, four had worked specifically with endometriosis for more than five years, and all of them had made researches and had published works related to this disease. Thus, even though the participation of nurses was not considerable, doctors contributed with the nursing field, because they determined data which were produced by nurses who are relevant to the medical clinic.

Archetypes

We prepared three use cases diagrams: use cases interaction diagram for professionals to EHR, use cases diagram with nursing care to patients, and use cases diagrams on nursing treatment to the women with endometriosis records, all of them considered essential basis for the archetype development.

ESSENTIAL NURSING DATA SET TO THE TREATMENT OF WOMEN WITH ENDOMETRIOSIS – CDEEPE	
HISTORIC OF NURSING AND PHYSICAL EXAM	
IDENTIFICATION	
1. Name: 2. Date of birth: ____/____/____ 3. Age: 4. Gender: 5. nationality: 9. Origin: () Home () Basic Health Care Unit () First aid post () General Hospital () Clinic/Center of Endometriosis () Emergency room () Others: _____	6. Race: () white () brown () black () Indian 7. Schooling: () Elementary school () High school () Graduation () Post-Graduation 8. Occupation: 10. Informer: () Patient () Family member () Friend () Health professional () Others: _____
11. Central complaint:	12. Medical diagnostic:
PERCEPTIONS AND EXPECTATION RELATED TO THE PATHOLOGY	
13. Reasons for hospitalization: () surgery () treatment () Exams () procedures () Others: _____	14. History of present illness: 14.1. Patient and her family knowledge about the pathology and its treatment: () yes () No () only patient
15. Previous history: Menarche age: _____ Menopause: () No () Yes - Age: _____ Menstrual cycle: () Inferior to 25 days () 25 days () Between 25 and 32 days () More than 32 days Menstrual flow: () small amount () moderate amount () great amount Menstruation time: () until 5 days () 7 to 10 days () More than 10 days Parturition: () Nulliparous () Primiparous () Multiparous Kind of parturition: () Normal () Cesarean Surgery: () None () Hysterectomy () Removal of tumor () Oophorectomy () Salpingectomy () Cystectomy () Others: _____ Abdominal surgical scar: () Yes, without changes () Yes, with changes () No Confirmed Diagnosis of Endometriosis, watch out: () Recurrence after medication () Localization of injuries () Degree of organs compromising Kind of Endometriosis: () Superficial () Peritoneal () Ovarian () Deep infiltrating () Extraperitoneal () Others: _____	16. Health conditions: Pathology or present alterations: () Diabetes, kind: _____ () Systemic arterial hypertension. Stage: () 1 [140-159/90-99 mmHg], () 2 [\geq 160/ \geq 100] () Asthma () Allergies: () Eczema () Fibromyalgia () Thrombosis () Varicose Veins () Other circulatory diseases. What? _____ () Anatomical distortion () cysts () Cancer. _____ () Neurological Diseases. What? _____ () Sexually transmitted diseases () Others. _____ Risk factors: () Tobacco () Alcohol () Other drugs If you use any of the above, report the frequency of use: _____ Contraceptive method: () None () Hormonal pill () Copper-bearing IUD () Schedule/Calendar () Basal temperature () Billing / Cervical Mucus () Withdrawal () Preservatives () Hormonal Endoceptive () Hormonal implant () Others: _____ Time of use: _____

Picture 2 – Part of the nursing data set, essential to the treatment of women with endometriosis. Curitiba, PR, Brazil, 2011.

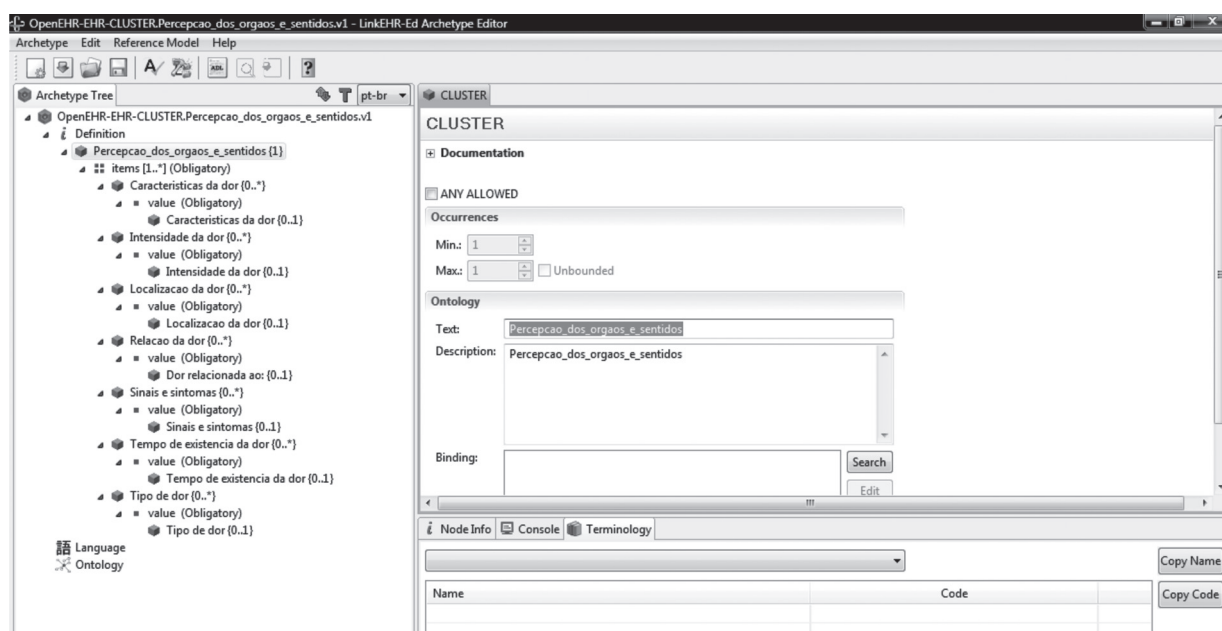
Regarding archetype, we picked up the item “Perception of the Organs and the Senses”, with their respective elements, involving “pain” and “signs and symptoms”. Such elements are extremely important to women with endometriosis care, because they involve unpleasant situations and common problems in their lives, such as, for example: dysmenorrhea (pain during menstruation); dyspareunia (pain during the sexual intercourse); dysuria (pain to urinate); Points of Pain; Pain intensity, among other problems resulting from the sense of “PAIN” and “SIGNS AND SYMPTOMS”. The archetypes may be constructed as the example on Picture 3.

Picture 4 shows the mapping process from part of the chosen item in CDEEPE, the Archetype Tree structure and the specification in ADL (Language of Archetype Definition) language.

Looking at 5 we can notice an example of an EHR interface, holding some CDEEPE data. Screens are important to show how the record of necessary data on nursing treatment can be done.

DISCUSSION

CDEEPE items concerning to nursing care data got special attention, considering that they were related to nursing treatment. Elements re-



Picture 3 – Archetype “Perception of the Organs and the Senses”. Curitiba, PR, Brazil, 2011.

cords hold by the item Nursing History and Physical Exam is the first step of treatment, when all the biological, social, spiritual and physical needs of the patient are collected.

An important background element that must be observed is the need of organs and senses perception, in which pain is highlighted. It must present information about pain: localization, type, characteristics, intensity, time of existence, and position in which pain is decreased. It must also include data about dysmenorrheal occurrence, dyspareunia, cramps, dysuria and pain to excrete, besides other ordinary endometriosis signs and symptoms. All these needs were found out due to specific symptoms, medicine effects when women reproductive plans help determining the care plan to these patients.

Regarding Physical Examination, nutrition and hydration, urinary elimination, intestinal elimination and physical security are extremely important to the treatment of patients with endometriosis, because such data involve harm development.

Nursing Diagnosis was based on NANDA International⁽¹³⁾ and on CIPETM/CIPESCTM⁽¹⁴⁾. Diagnosis based on CIPETM are related to the reproductive tract process⁽¹⁵⁾ and the pain process⁽¹⁶⁾, in order to adequate nursing practices to the environment. However, some diagnosis can also be used as nursing results. Thus, CIPETM terms embrace

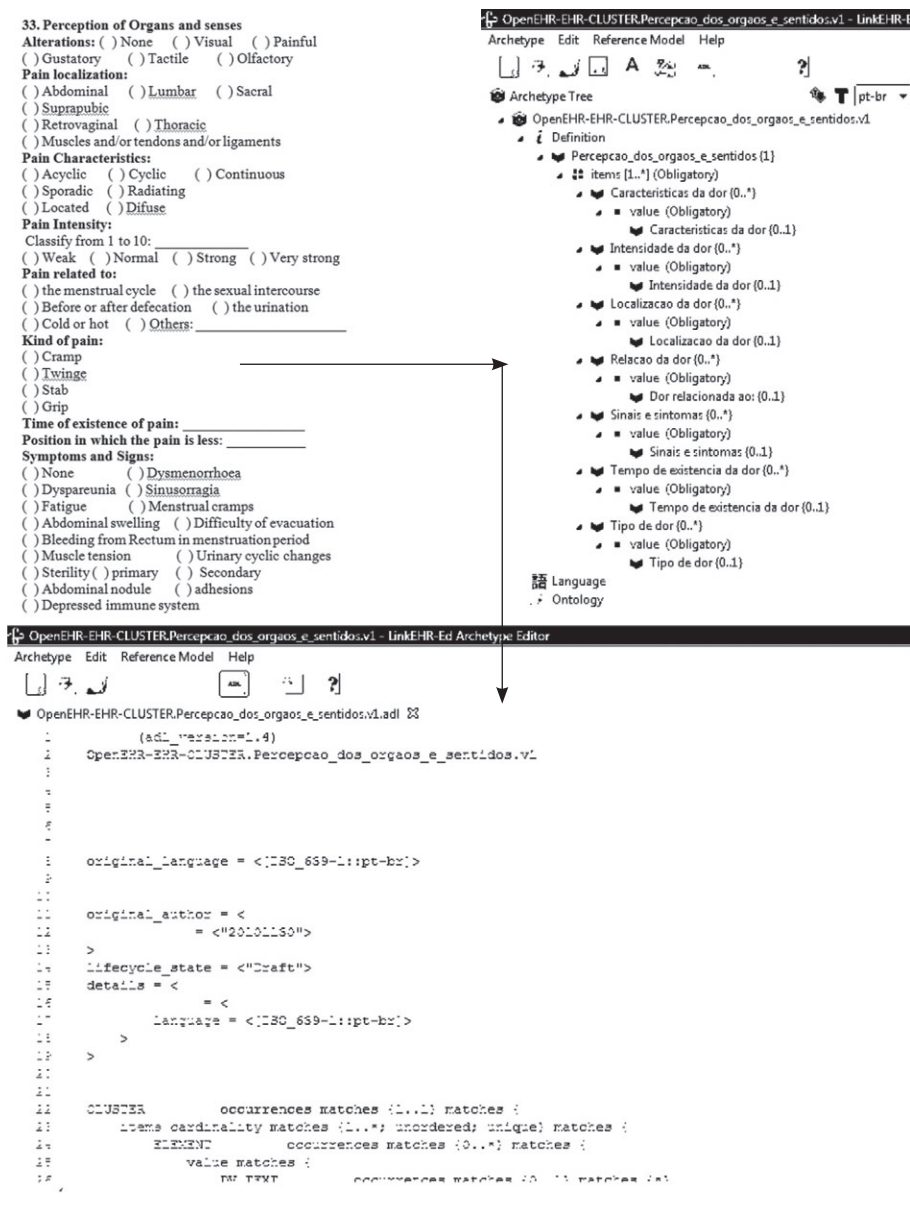
its utilization in respect to nursing practices in ordinary and present situations on these women's life, problems as reproductive organs removal, miscarriage and infertility, besides pain, that is usual in most parts of symptomatic women with endometriosis, varying in intensity and location.

It is important to highlight the terminology indications to be used for information determination, it is essential to the data set implementations.

Both NANDA I and CIPETM are well-structured, with some distinct features, depending on treatment standardization in accordance to the work environment. Proposing the two terminologies had the aim of expanding the information, providing choices according to standard terminology used in such institution. So, CDEEPE can be adequate to any nursing work environment. These classificatory systems have the intention of theoretical improvement and practical nursing knowledge in common, qualifying the information provided by nurses⁽¹⁷⁾.

Nursing Interventions focused more on peri-operative treatment, because the set was based on the literature; so interventions on endometriosis were found during surgical nursing attendance. Nursing interventions must be based on a nursing treatment plan, with responsibility and accuracy, answering to the selected diagnosis.

Nursing Results is also necessary to evaluate which intervention was performed and whether



Picture 4 – Archetype development process mapping. Curitiba, PR, Brazil, 2011.

data were accordingly collected, whether they answer to the nursing diagnosis and whether the care plan matches what was answered. Which means that a logical and coherent performance actions sequence must exist, and then evaluate whether the results have been achieved.

The Nursing Evolution item must be associated to every nursing treatment moment, because, subsequently to the background, it is going to follow up what was done during attendance, collecting subjective data, goals and procedures according to the diagnosis and prescriptions, exams and changes,

whether the results were achieved, justifying if they were not.

EHRs are more becoming important and necessary day after day and, and it must have specific information to attend data standardization and communication requirements on health field. Nowadays, the use of implanted experience archetypes with this systems is limited, but we believe it will have further positive trends on interoperability⁽¹⁹⁾. Thus, it is essential that data sets be specified considering patterns, specially the archetypes⁽²⁰⁾ and the requirements to the development of an EHR. A multidis-

Picture 5 – Screen example with data on Perception of the Organs and the Senses. Curitiba, PR, Brazil, 2011.

ciplinary view over these sets is also important, once different professionals who work with patient care will have access to the information. Therefore, doctors and nurses took part on the formal study.

The difficult times faced regarding experts participation that usually happen on researches done by e-mail, with absenteeism rates around 30 to 50%, was particularly larger in the current work, due to few nurses actions in the treatment of women with endometriosis. However, even with a small absolute amount of 2 nurses, they were representative, considering their work on the particular field. Besides, the average of 95,9% on the answers shows that the information proposed on CDEEPE are essential to an adequate treatment, easing integration between doctors and nurses. Another point to be discussed is that data set specifications tend to make professional performance easier on the field. Thus, the first version of a data set is the best way to make the activity and the knowledge easier. CDEEPE certainly will make it possible

to more nurses to get to know this disease can be better treated in women suffering with it. So, they will contribute to refine this data set.

It is difficult to find nursing professionals, in Brazil, who provide assistance to women with endometriosis, once the role of the nurse was always more related to demands associated to pregnancy and childbirth. However, in other countries, this kind of treatment is guaranteed and considered important⁽¹²⁾.

Nurses who participated in this research stated that they do not know a nursing treatment, to women with endometriosis, developed in Brazil. It is true that the nursing work is seen in any activity that provides assistance to human beings. However, regarding such work involving endometriosis, it must be recognized and contemplated. The authors⁽¹¹⁾ describe the importance of nursing assistance of patients with endometriosis caring.

In order to turn nursing work more visible, nurses must establish what data are essential to

EHRs, as well as the implemented terminologies, and the archetypes that can be effective on the implementation of such sets to make the records. We also highlight that besides reinforcing the development of EHRs, archetypes make the knowledge representation possible for the expert's domain, who are the nurses performing the work. It allows the information systems to be specified along with its users.

CONCLUSIONS

CDEEPE production enclosed necessary and important information on the nursing practice, contributing to EHR computerization and to the application of nursing processes regarding provided care. Nursing work must contribute during information gathering on patient's health situation, treatment and prognosis, in an effort to support and educate them.

During the research literature and CDEEPE formation process, it was evident that, besides the public policies on the endometriosis field, nursing field works on such harm are still rare, as well as professionals with experience on endometriosis care. These facts limited the number of participants during CDEEPE evaluation. Thus, the proposed set must be a great stimulus to organize and direct data collection on this field.

Far after, we demonstrated that it is important that archetypes and classificatory nursing systems be inserted on the computerized systems, what will make the nursing decision-making and clinical judgment possible, all based on patient treatment evidences, providing safe assistance and quality.

Essential data sets on nursing are important to the services' development and planning. Its utilization makes it possible to construct the basis to the evolution of research methods and evaluation related to nursing practices, substantially contributing to support the definition of the nursing roles on diverse contexts, including the one of endometriosis.

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