Management technology to mediate nursing consultation for people living with chagas disease

RESUMO | Objetivo: Construir e validar uma tecnologia gerencial, baseada no referencial teórico de Dorothea Orem, para mediar a consulta de enfermagem ao paciente com doença de chagas no Ambulatório de Cardiopatia Chagásica de uma instituição de ensino no município de Belém/Pa. Método: Pesquisa metodológica do tipo exploratória com abordagem quantitativa, realizada no período de maio a novembro de 2019, constituída em duas fases: elaboração do instrumento; submissão, avaliação e validação do instrumento por juízes especialistas. Resultados: Com exceção de um único item do instrumento, todo este foi validado com concordância de 95,12%. Conclusão: O instrumento validado contribuirá para a implementação da assistência a população. Os princípios da teoria do autocuidado são aplicáveis e pertinentes para planejar e avaliar a assistência aos pacientes que, neste estudo, especificamente, são os que vivem com doença de chagas, assim, este estudo proporciona aos enfermeiros um instrumento baseado em evidências científicas e validado por profissionais qualificados.
Palavras-chave: Doença de chagas; Enfermagem; Tecnologia.

ABSTRACT | Objective: To construct and validate a management technology, based on Dorothea Orem’s theoretical framework, to mediate the nursing consultation with patients with chagas disease at the Chagas Heart Disease Outpatient Clinic of an educational institution in the city of Belém/Pa. Method: Exploratory methodological research with quantitative approach, carried out from May to November 2019, consisting of two phases: elaboration of the instrument; submission, evaluation and validation of the instrument by expert judges. Results: With the exception of a single item of the instrument, the whole of this was validated with agreement of 95.12%. Conclusion: The validated instrument will contribute to the implementation of assistance to the population. The principles of the theory of self-care are applicable and pertinent to plan and evaluate care for patients who, in this study, specifically, are those living with Chagas disease, thus, this study provides nurses with an instrument based on scientific evidence and validated by qualified professionals.
Keywords: Chagas disease; Nursing; Technology.

RESUMEN | Objetivo: Construir y validar una tecnología de manejo, basada en el marco teórico de Dorothea Orem, para mediar la consulta de enfermería con pacientes con enfermedad de Chagas en el Ambulatorio de Cardiopatías de Chagas de una institución educativa de la ciudad de Belém/Pa. Método: Investigación metodológica exploratoria con enfoque cuantitativo, realizada de mayo a noviembre de 2019, constituida en dos fases: elaboración del instrumento; presentación, evaluación y validación del instrumento por jueces expertos. Resultados: Con la excepción de un solo ítem del instrumento, el conjunto de este fue validado con concordancia de 95.12%. Conclusión: El instrumento validado contribuirá a la implementación de la asistencia a la población. Los principios de la teoría del autocuidado son aplicables y pertinentes para planificar y evaluar la atención de los pacientes que, en este estudio, específicamente, son los que viven con la enfermedad de Chagas, por lo que este estudio brinda al enfermero un instrumento basado en evidencia científica y validado, por profesionales calificados.
Palabras claves: Enfermedad de chagas; Enfermería; Tecnología.

Ana Gracinda Ignação da Silva
Nurse. PhD in Nursing from the Federal University of Rio de Janeiro (UFRJ). Professor at the Metropolitan University Center of the Amazon (UNIFAMAZ). Belém, PA. ORCID: 0000-0001-6439-7842

Gabriel Fazzi Costa
Nurse. Master’s student in Parasitic Biology in the Amazon by the State University of Pará (UEPA) and Instituto Evandro Chagas (IET/UEPA). ORCID: 0000-0002-9672-5676.

Wanne Thaynara Vaz Guarjão
Nurse. Resident in Critical Patient Care at the Federal University of Pará (UFPA). Belém, PA. ORCID: 0000-0001-5026-6139

Fernanda Carmo dos Santos
Nurse. Resident in Urgency and Emergencies in Trauma by the University of the State of Pará (UEPA).

INTRODUCTION

Health technologies are conceptualized as a complex of actions, which include procedures, equipment, practices, techniques and instruments that, added to scientific knowledge, produce in the professional the skills and competences to recognize what, why, for whom and how to use such methods within user assistance. Such technologies cover the health area in three spheres: hard technologies (HT) are material resources; the light-hard technologies (LHT)
are structured knowledge and the light technologies (LT) are the relationships that occur.1

They can also be classified as educational technologies, which are methodical outlines of the production of knowledge, which encompass the actions of planning, executing, controlling and monitoring the educational process, formal or informal. Assistive technologies, which involve the construction of technical-scientific knowledge resulting from an evidence-based practice, which aims at systematized, procedural and instrumental attitudes for the provision of qualified assistance, and management technologies, which are methods created and implemented in the sectors of health in order to intervene in the daily professional practice, seeking improvements in care services.2

Technological instruments are present in daily nursing practice, as they speed up the capture of crucial information for the planning and implementation of care, enabling organizational control.3

Nursing is based on scientific and humanistic care, which aims to restore health.4 In view of the patient’s clinical condition, the importance of the nursing consultation (NC) is understood, which promotes the construction of bonds between nurses and the individual, their families and the community, as well as a space for health education. One of the methods to properly guide the NC.5

The nursing consultation must be based on technical-scientific knowledge, organized by the Nursing Process (NP) and based on a theoretical model, with a view to determining the needs of this clientele.6

In a context of care that involves user participation, a theoretical model that promotes this professional/user relationship in a learning perspective is essential, such as the Nursing Self-Care Deficit Theory proposed by Dorothea

Elizabeth Orem, which helps nurses’ understanding of patients’ human systems and relationships. It is a theory that explains self-care as a human regulatory function that individuals must perform for themselves or have performed for them through dependent care or nursing care.7

Considering the context of Chagas Disease (CD), it is noteworthy that it is caused by Trypanosoma cruzi, transmitted mainly by an insect, commonly known as “barber” – Triatoma infestans. It is a disease that affects regions with low quality of basic sanitation and high poverty rates, therefore, nurses who work in riverside communities, countryside and forest and even in capitals, have great difficulty in carrying out control measures, as there is an intense consumption and planting of açai, present in northern culture, especially in Pará, as well as sugarcane in the Amazon region, noting that the main means of transmission of the disease today is oral and vector.8

According to Simões9 worldwide, there are 8 million people with CD, in Latin America there are 300.00 thousand infected people and, in accordance with the data from the DataSus of 2012 – 2017, there are 1.546 confirmed cases of acute CD in Brazil and, of these, 1.504 are present in the North of the country, with high prevalence in the municipalities of Ananindeua – 324, followed by Abaetetuba – 219, Breves – 175 and the capital Belém with 147 cases.10

Considering these aspects, this study brings visibility to nursing as an important part of care for patients living with Chagas disease, building records and knowledge about this care, which will certainly contribute to the professional training of nurses. It is known that the proposal of an instrument based on nursing theory facilitates data collection and application of nursing diagnoses and intervention.11

It is also important to emphasize the need for a technology to guide nursing consultations, since CD is neglected in several regions, as well as the Amazon region, even though it is an endemic place with a high incidence of cases.12

This research had as a guiding question: Does the development and validation of an instrument to mediate the nursing consultation with patients living with Chagas disease present an acceptable level of agreement to constitute a management technology? And it aimed to build and validate a management, based on the theoretical framework of Dorothea Orem, to mediate nursing consultations to patients with Chagas disease at the Chagas Heart Disease Outpatient Clinic of the Metropolitan University Center of the Amazon - UNFAMAZ, in the city of Belém.

METHOD

Exploratory methodological research with a quantitative approach. Methodological studies deal with the development, validation and evaluation of instruments. This study aims to verify the level of agreement of expert judges on the instrument built to mediate nursing consultations for patients with CD.

It has two phases: “development of the instrument” and “submission of evaluation; validation of the instrument and adequacy of the final instrument”. All based on Moura’s study13, which emphasizes validation in two stages: the first constitutes the development of the instrument and the second involves the analysis and judgment of experts. The Pasqualli model was also used, which includes, among others, the theoretical foundation for the construct for which a measurement instrument is to be developed, and the analytical procedures, which determine the statistical analysis of the data with a view to validating the developed instrument14.

1st phase - Preparation of the instrument: To this end, an Integrative Re-
view (IR) was carried out in the Latin American and Caribbean Literature in Health Sciences (LILACS), Online Me-
dical Literature Analysis and Retrieval System (MEDLINE) and Nursing Da-
tabases (BDENF) databases, using the descriptors: “Doença de Chagas (Chagas disease)”; “Teorias de Enfermagem (Nursing theories)” and “autocuidado

**FIGURE 1: INSTRUMENT EVALUATION QUESTIONNAIRE**

![Image of the evaluation questionnaire]

**FIGURA 2: QUESTIONÁRIO DE AVALIAÇÃO DO INSTRUMENTO (CONTINUAÇÃO)**

![Image of the continuation of the evaluation questionnaire]

SOURCE: AUTHORS, 2019 *see the translation in the appendix A*
The development of the technology took place from May to July 2019 and consisted of selecting the content based on evidence in the literature and the theoretical framework of Dorothea Orem. An exhaustive reading of the articles was carried out in search of evidence for the development of the instrument. From the in-depth study of Dorothea Orem’s theoretical framework, the main characteristics for the instrument to be proposed were established in four categories: Personal Factors and Basic Conditioning; Self-Care Requirements in Health Deviations; Developmental Self-Care Requirements and Universal Self-Care Requirements.

2nd phase: Submission of evaluation, validation and adequacy of the instrument: This phase only started after submission of the project by the Research Ethics Committee of UNIFAMA, CAAE: 14621019.4.0000.5701 as per opinion number 3.421.643, all judges signed the Informed Consent Form - ICF, which was attached to the evaluation kit.

Twelve expert judges were selected, of which the evaluation of one judge was discarded, as this one did not completely fill out the evaluation instrument.

The instrument’s content was evaluated in relation to agreement: four specialist nurses in the area of Chagas disease; three specialists in primary care; two with experience in instrument construction; one with experience in nursing theories; and a Ph.D. in pedagogy who has experience in teaching in the field of nursing.

The content validity index (CVI) was used to assess the level of agreement between these judges, which must be equal to or greater than 80% (CVI>0.8). Items with a lower percentage were excluded or adapted as suggested by the judges. In this study, the overall agreement percentage of 95.12% was reached.

The selection criteria for expert judges in the field of nursing were: To have at least three years of experience in their field; have a graduate degree; have experience as a teacher and/or as a nurse in the area of primary care and/or in the care of patients living with Chagas disease and also experience with the systematization of nursing care.

For the evaluation of the instrument by the judges, a validation form was built with measurable indicators (Likert scale type) contemplating scores from 1 to 4. Where 1 is totally inadequate; 2 is partially adequate; 3 is adequate and 4 is totally adequate. To assess the instrument, the form was divided into: relevance, clarity and organization, coherence, structure, comments and suggestions from the judges, as shown in figures 1 and 2.

A validation kit was prepared containing a copy of the technology to be evaluated, the ICF in two copies and the evaluation form, and the return of the completed form and a copy of the signed ICF was requested, within a period of fifteen days, which was complied with.

The data obtained were tabulated with the help of Microsoft Excel and quantitatively analyzed using descriptive statistics. To analyze the agreement of the judges’ responses regarding the content validation of the proposed instrument, the frequency of responses was analyzed, as well as the descriptive analysis of the judges’ suggestions for changes and expressed in graphs, in order to demonstrate the agreement between the responses of the judges as to the content of the instrument’s items.

To incorporate the judges’ suggestions into the instrument, the percentage obtained for each item was considered. Items that had a total score of less than 80% for any of the evaluated criteria were changed or excluded from the instrument. The judge’s justification or suggestion to proceed with the change was also considered. In this case, only one item of the instrument had a score below 80%, and it was related to “how was it diagnosed?” for better understanding.

RESULTS

Based on the Integrative Review that supported the research theme and on the expert judges’ evaluation, two major themes were evidenced through which the instrument construction and validation process was described, as follows.

Construction of the instrument for nursing consultations for patients living with Chagas disease

The integrative review for content search consisted of five articles that met the inclusion criteria, one from the Latin American and Caribbean Literature Database in Health Sciences (LILACS) and four from the Nursing Database (BDENF) with the descriptors “Doença de chagas”; “Teorias de enfermagem” and “autocuidado”. It was not identified in these scientific articles an instrument that would support the nursing consultation of patients with Chagas disease with a focus on self-care.

The authors related the individual findings of the main occurrences and complications of people living with Chagas disease to the main foundations of Dorothea Orem’s theory of self-care deficit for the construction of the body of the final instrument.

The main focus of the instrument, a priori, was to meet the outpatient demands and primary health care, to be used in the first nursing consultation, which involves a historical, family, personal and economic survey.

The final instrument consists of topics based on Dorothea Orem’s theory of self-care deficit: Identification; Socioeconomic data; Universal requirements; development requirements; in relation to Chagas disease (CD);
and health diversion requirements. In addition to containing a table created from the main foundations of Dorothea Orem’s theory, to classify the level of self-care deficit. The development of the table is intended to help nurses to determine the degree of deficit of the patient, helping the professional to create a care plan for this patient. A sheet for recording nursing diagnoses, expected results, interventions and assessment of the nurse was assigned, as shown in Appendix A.

Validation of the instrument with expert judges (EJ) and pedagogical judges (PJ)

Specialist Judges are aged between 28 and 64 years; most females (90%); eight had more than 10 years of training; 80% work in the teaching area and 30% in the primary care area; eight with more than 10 years of practice and two with less than 10 years of experience. As for the title, two specialists, five with a master’s degree and three with a doctorate. PJ is 43 years old, male, graduated for more than 10 years, has been working in teaching for over 10 years, his degree is a doctorate.

The following describes each category evaluated and validated in the instrument: Socioeconomic data; universal requirements; development requirements; in relation to Chagas disease; health diversion requirements; assessment table of self-care deficit and instrument appearance.

Categoría dos dados socioeconômicos

In validating the instrument’s content, the sociodemographic items are:

Region: Quilombola/Field/Forest/Urban;
Housing conditions: Wood/ Masonry/ Pau-a-pique/ Others;
Number of people residing;
Room numbers;
There are indoor bathrooms;
Water treatment / septic tank;
Lives close to: Açaí palm plantations/ Animal husbandry/ Forest;
Family income. Relevance, clarity, organization were considered, as shown in graphs 1 and 2 below.

In this category, no item was rated below 90% by expert judges, the pertinence aspect had an average of 94%, clarity 100% and organization 98%. The judges had an average agreement of 97% in this category. In this way, all items were validated. The CVI for this category was 100% according to JP, the pertinence, clarity and organization averages were also 100%.

The suggestion made by a JE and the JP was to place indigenous people in the item region; another expert judge suggested adding the item that investigates whether the patient has traveled to the interior of the state or to another state in the last month and about investigating whether the roof or roof of the house is thatched. What was accepted and added to the final instrument.

Universal requirements category

Content validation is related to: Number of daily meals; most frequent foods in the diet; How many times a week do you take açai and/or sugarca- ne juice; Açai/cane juice is: purchased/ own production; do you treat the açai/ cane juice, how is it treated? Only in tap water/ Bleaching/ Pasteurization/ Other form; if there is bleaching, do you follow the 4 steps? Washing in running water/ Submersion in water with hypochlorite/ Immersion in water at 80° C/ Chilled in cold water; water intake; Bladder elimination: Urinary retention;
Intestinal elimination; sleep and rest. In the Universal Requirements category, relevance was 97%; 96% clarity and 95% organization. With the average agreement between judges of 96% and as in the previous category, no requirement scored less than 90%.

In this requirement, in line with JP’s assessment, it had an overall average of 100%. Two JE suggested increasing the space for the answer in item 2; two judges suggested adding an item related to the consumption of undercooked wild meat and yet one judge suggested modifying the whitening item for better understanding. Another judge suggested adding a “river water” item to the item “water that consumes” and one suggested removing the last two questions from the category, related to sleep and rest.

Development requirement category

Regarding the development requirements category, the criteria included were: Comorbidities; Risk behavior: Smoking/ Alcoholism/ Drugs/ Others; HIV positive; transplanted; immunosuppressants; the 5 senses are preserved; if not, specify: Sight/ Taste/ Touch/ Smell; cognitive or motor deficit? if you have a lot of difficulties, there is someone to help you with your daily activities; which relationship.

The average agreement for this requirement was 94%. 95% for relevance and 94% for clarity and organization. There was an overall average in this requirement of 100% by PJ, and the characteristics of relevance, clarity and organization obtained results equal to the overall average.

In this category, a JE suggested the detailing of the comorbidity item; adding – unable to answer – to the item that investigates HIV-positive risk behavior and removing the degree of kinship in item 10 of the instrument. A third option was added to the item “immunosuppressants” containing “does not know how to inform”. We attended to the final instrument.

Category in relation to chagas disease

For the category related to Chagas disease, the items covered are Acute/ Chronic Phase; contamination: Oral/ Vector/ Transfusion/ Congenital/ Ac. Laboratory/ Sexual; family members with the same diagnosis; how did you react to the diagnosis of the disease? Main signs and symptoms: Fever/ Headache/ Myalgia/ Tachycardia/ Pallor/ Edema/ Others; Hospitalization - if yes, for how long? How was it diagnosed? How long ago was it diagnosed? Did you under-
go treatment? Start/ End/ Not Ended; which treatment performed? - Dose per day; in outpatient follow-up? Which side effects; guidelines regarding the disease? Which ones, to which he managed to adapt; do you show interest in improving your self-care?

In this category, the average agreement was 96%, with 96% for pertinence, organization and 94% for clarity. The following modifications were suggested by the EJ: From item 2, where it is – family members – for family members and close people; in item 4, the addition of – fatigue, swelling around the eyes and malaise; in item 11 – addition of drug side effects; in item 12 – if you can follow the guidelines about the disease and treatment. All were included in the final instrument.

Item 6 in this category was the only one among the entire instrument that received less than 80% agreement on the clarity requirement, being changed for better understanding.

Health deviation requirement category

Related to items: Coping with the disease currently: Fear/ Anxiety/ Worry/ others; Current complaint; changes in Clinical/ Laboratory/ Images in: Heart/ Esophagus/ Colon/ sequelae? - which?; Tiredness with small and medium efforts; Vital signs: Temperature/ Heart Rate/ Respiratory Rate/ Blood Pressure; Laboratory and imaging tests: Physical examination/electrocardiogram: GGC (Good general condition)/ PGC (Poor general condition)/ RGC (Regular general condition); Head and neck exam: Presence of Romané sign/ Other findings; Circulatory function test: CF: BNF 2T/ Bradycardia/ Tachycardia/ Arrhythmia/ Murmur/ Gallop/ Other findings; Chest exam: Respiratory function; Other findings; Abdomen Exams: Digestive Function; Auscultation; Percussion; Palpation; Hepatosplenomegaly; pain on palpation; if yes, quadrant/ Other findings; Motor function.

The average agreement was 97% and the lowest percentage in the IVC was 80%, in the organization’s requirement. Regarding relevance and clarity, they had an arithmetic mean of 98% and organization 97%. The pertinence, clarity and organization averaged were also 100%. One judge suggested adding item 1 to item 2, with this the authors decided to also group item 5 to item 2. Three judges suggested modifications in item 3, related to changes in clinical examinations; of these, two recommended adding the item related to laboratory and imaging tests, so these items were grouped, one judge asked for more space to describe the changes found.

Self-care deficit table category

As for the item related to the classification of self-care deficit, the average agreement was 90%, and for relevance, clarity and organization it was 90%. The average agreement was 100%, and for relevance, clarity and organization it was 100%.

Diagnostic/result/intervention classification of nursing

In this item, a Ej suggested that the word guidance be removed, leaving only the word intervention and adding evaluation/evolution. The inclusion of – date of withdrawal of the nursing diagnosis was also suggested. What was attended to for the final instrument. The Nursing Diagnosis/Result/Intervention Record Classification requirement had an average of 100%.

Instrument appearance category

This category deals with the evaluation of the instrument’s appearance, which includes: clarity and objectivity; Logical sequence of the proposed content; structured in concordance and spelling; aesthetically suitable; instrument layout; font type and size; writing style; allows the nurse to add information; it can be adopted in nursing consultations for patients with Chagas disease.

In this category, the average agreement was 95%. In the evaluation of appearance, the CVI was carried out with nine judges, as one of them failed to fill in this part of the form. There was no suggestion as to the instrument's appearance.

DISCUSSION

Article 3 of Law 8080 discusses the determinants and conditions in health and what they are and offer the health professional an overview of the socioeconomic situation to which their clientele belongs, so that, based on the nurses’ understanding of the reality of the user is able to establish individualized and integrated care.15

The first part of the instrument addresses this purpose. It is intended to capture key information about the most varied aspects of the user’s reality and the infrastructures that surround him.

After this first moment, the nursing care model proposed by Dorothea Orem begins. The instrument managed to support the five central concepts (self-care capabilities, self-care actions, therapeutic self-care demands, self-care deficit and nursing training) and a secondary one (universal requirements, health development and deviation) of the theory.18

Despite the instrument’s structure being based on the secondary concept, care was taken to introduce the objects foreseen in the theory's central concepts in the requirements, using the entire scientific framework proposed by the TDAE.

The development requirements are related to the capacity for self-care, in which the first is related to new events that affect human life, such as acquiring some comorbidity, in which the latter must adapt to a new routine to maintain their well-being, the second, are actions that people can carry out by themselves.16
Regarding Chagas disease, its phases, acute and chronic, which can be presented in an asymptomatic and symptomatic way, were addressed, and in the acute form it is possible to notice the presence of free Trypanosoma cruzi in the bloodstream. When its symptoms are present, it triggers prolonged fever, headache, facial edema – Romaná’s sign, tachycardia, pallor and asthenia.9

While, in the chronic symptomatic form, serology is reactive to the parasite, with possible cardiac involvement such as heart failure syndrome, arrhythmias, as well as gastrointestinal disorders, such as hepatosplenomegaly and megaesophagus.9

In the health deviation requirement, the aspects of the physical examination were presented, directing and filtering the possible findings found in patients with Chagas disease. It is known that from a good anamnesis, the main problems that generate nursing diagnoses and interventions are extracted.16

The framework is based on the concepts of Self-care Deficit and Nursing Capacity, since after completing the instrument, the nurse has enough information to measure the client’s self-care capacities and demands, as well as to establish a line of action aimed at the reestablishment of capacities and the reduction of demands.16

CONCLUSION

The proposed instrument was evaluated by ten (10) expert judges and one (1) pedagogical judge, and validated with 95.12%. It was planned and built based on sociodemographic data, which characterize the patient and their social and economic context. Its direction was Oren’s nursing theory. In the universal requirements of the theory, it considers data referring to food, hydration, elimination, sleep and rest. In the developmental data, referring to risk behavior, such as drug use, smoking, alcoholic beverages, sexually transmitted diseases, as well as those related to the five senses and cognitive or motor deficits.

The instrument also addresses aspects related to the stage of the disease, whether acute or chronic, type of contamination, signs and symptoms, treatment, side effects. Added to the health deviation requirements, which includes patient responses to their disease condition, which includes anxieties, fears, concerns, laboratory and imaging changes and functional cardiopulmonary, gastric, circulatory and motor responses.

The study is expected to contribute with help to nurses and nursing students in consulting patients with Chagas disease, enabling them to help both in the necessary care and in health education for them and their families, necessary to avoid the worsening of symptoms and complications inherent to these patients.8

References

APPENDIX-A