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Construction and validation of an instrument for the registration of children and adolescents with chronic illness[*]

Construção e validação de instrumento para cadastro de crianças e adolescentes com doença crônica

Construcción y validación de un instrumento para registro de niños y adolescentes con enfermedades crónicas

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This study aims to describe the construction and validation of a tool for the registration of children and adolescents with chronic illness. This is a methodological research, with the application of the Delphi method, in two stages with five judges and a pilot test with the participation of caregivers of children and adolescents, carried out between 2014 and 2016. For the construction of the tool, a review and research was carried out in other tools used by health information systems. To analyze the relevance of variables, the percentage of agreement between judges was used, with a cutoff point of 80%, the final version was approved by 100% of the judges with a Cronbach's Alpha of 0.89. In the validation process, the judges issued an opinion on the tool's attributes, which were organized and grouped by content analysis into: *Highlighting the positive aspects of the instrument* and *Limitations presented by the instrument*. Two versions reviewed by the judges were considered, so that the validated tool reached 131 questions, proving to be appropriate for health services that serve the public, with a view to identifying and surveying and monitoring social, economic conditions, as well as the process health and illness, service network accessed by the family and family dynamics of children and adolescents with chronic illness.

Descriptors: Validation study; Data collection; Chronic disease; Child; Adolescent.

Este estudo tem como objetivo descrever a construção e validação de um instrumento de cadastro de crianças e adolescentes com doença crônica. Esta é uma pesquisa metodológica, com aplicação da técnica Delphi, em duas etapas com cinco juízes e um teste piloto com a participação dos cuidadores das crianças e adolescentes, realizado entre 2014 a 2016. Para a construção do instrumento foi realizada revisão e pesquisa em outros instrumentos utilizados por sistemas de informação em saúde. Para análise das pertinências das variáveis, utilizou-se o percentual de concordância entre os juízes de com ponto de corte de 80%, a versão final foi aprovada por 100% dos juízes com alpha de *Cronbach* 0,89. No processo de validação, os juízes emitiram parecer sobre os atributos do instrumento, estes foram organizados e agrupados pela análise de conteúdo em: *Destacando os aspectos positivos do instrumento* e *Limitações apresentadas pelo instrumento.* Foram consideradas duas versões revistas pelos juízes, de modo que o instrumento validado alcançou 131 questões, mostrando-se adequado para os serviços de saúde que atendem o público com vistas a identificação e o levantamento e acompanhamento das condições sociais, econômicas, bem como do processo saúde e doença, rede de serviços acessada pela família e dinâmica familiar da criança e adolescente com doença crônica.

Descritores: Estudos de validação; Coleta de dados; Doença crônica; Criança; Adolescente.

Este estudio tiene como objetivo describir la construcción y validación de un instrumento de registro de niños y adolescentes con enfermedades crónicas. Esta es una investigación metodológica, con aplicación de la técnica Delphi, en dos etapas con cinco jueces y una prueba piloto con la participación de los cuidadores de los niños y adolescentes, realizada entre 2014 y 2016. Para la construcción del instrumento, se realizó una revisión e investigación en otros instrumentos utilizados por sistemas de información en salud. Para analizar la pertinencia de las variables, se utilizó el porcentaje de acuerdo entre los jueces con un punto de corte del 80%, la versión final fue aprobada por el 100% de los jueces con un alfa de *Cronbach* de 0,89. En el proceso de validación, los jueces emitieron una opinión sobre los atributos del instrumento, que fueron organizados y agrupados por análisis de contenido en: *Destacando los aspectos positivos del instrumento* y *Limitaciones que presenta el instrumento.* Se consideraron dos versiones revisadas por los jueces, por lo que el instrumento validado llegó a 131 preguntas, mostrándose adecuado para los servicios de salud que atienden al público con miras a la identificación y el estudio y el seguimiento de las condiciones sociales y económicas, así como el proceso de salud y enfermedad, la red de servicios a los que accede la familia y la dinámica familiar de los niños y adolescentes con enfermedades crónicas.

Descriptores: Estudio de validación; Recolección de datos; Enfermedad crónica; Niño; Adolescente.

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INTRODUCTION

Chronic illnesses have been the object of study and interest in several areas of the health field, as they involve the sick person, their family, the multidisciplinary team and the service network[1-3] and, subjectively, influences related to the environment, the culture, the socioeconomic condition in which children, adolescents and their families live[4,5]. Chronic illnesses (CI) are widely discussed in adulthood, but information about the number of children and adolescents affected by these conditions in Brazil is still scarce and important data for planning, managing and caring for this population are incipient.

A study points out that CI overload health systems and affect more the low-income population, since this population is vulnerable, exposed to risk situations and has less access to health services[6]. Children and adolescents affected by chronic illnesses suffer losses in relation to years of schooling due to prolonged and frequent hospitalizations, as well as changes in family dynamics[7,8]. Other determinants of children's health are living conditions (structure, presence of windows, adequate flooring, natural lighting, electricity, treated water, basic sanitation and presence of animals)[9].

In general, a child or adolescent with a chronic illness and their family are assisted in health services by a multidisciplinary team, which must consider the family as the focus of care, including it in assistance[2-10]. In this context, the use of validated instruments that make it possible to record and obtain information about caregivers, the family context, the chronic illness, the service network, can expand the possibilities of care.

The process of constructing and validating an instrument must be guided by a need, and adequate methods must be employed to guarantee its validity, reliability and scientific recognition. The construction must be preceded by steps that comprise the synthesis of knowledge produced from available publications, participation of the target population, construction of the prototype and validation of the content by experts[11,12].

Content validation refers to the instrument’s judgment as to its ability to address the different aspects of the problem being investigated. It is also necessary that the instrument does not to contain elements that can be attributed to other problems. Based on the judgment of expert judges on the subject, the representativeness of items that express a content or problem is determined[13]. In addition to validity, another indispensable quality to give confidence to an instrument is reliability, which can be measured by the internal consistency given by Cronbach's Alpha. This measure is based on the correlation of the items that make up each dimension of the instrument. Values above 0.70 indicate satisfactory internal consistency for new instruments[14].

A review study listed the validated instruments to be used in the care process for children and adolescents with chronic illnesses in various health services and showed that there is still no instrument for registration and monitoring to compose a database[15]. In this sense, the collection of specific data for registration and monitoring of children and adolescents with CI can be a strategy to provide visibility.

This study is justified by the need for an instrument that enables the registration of this population and addresses the social, economic, illness-related aspects, the service network accessed and the family of the child/adolescent to contribute to the knowledge of the needs of the subjects involved and support decision-making in health. Thus, this study aims to describe the construction and validation of an instrument for registering children and adolescents with chronic illness.

METHODS

It is a methodological research, of the applied type, which resulted in the construction and content validation of a data collection instrument, which was operationalized in two phases: instrument elaboration and then the validation phase was initiated in October 2014 and completed in January 2016, using the Delphi method.

In the first phase of the research, the following criteria were followed: an integrative review on the topic[15], a theoretical basis[16] and consultation of similar instruments used by health information systems, such as: *Sistema para Informatização dos Dados de Registros Hospitalares de Câncer do Instituto Nacional do Câncer* - SISRHC (System for Computerization of Data from Hospital Cancer Records of the National Institute of Cancer) and the *Formulário de Cadastro Individual do Sistema de Informação da Atenção Básica* - SISAB (Individual Registration Form of the Primary Care Information System), from which representative variables of the studied theme were included.

Next, a prototype of the registration instrument was built, consisting of the main dimensions that comprise chronic illness in children and adolescents, namely: 1) identification data: full name, race/color, place of birth and residence, educational level, among others; 2) socio-sanitary data: housing situation, number of rooms, residents, presence of domestic animals, access to and treatment of water, garbage collection, among others; 3) illness and treatment: medical diagnosis, illness stages, access to medication, restrictions, hospitalizations, multidisciplinary team, care dependence, among others; 4) health network and services: access to the family health team, specialized clinic, referral hospital, among others; 5) family dynamics: involvement in care, sources of support received, segregation/family union after the illness.

The second phase followed with the validation of the content[13-17] which refers to the judgment of the instrument and its ability to cover all the important aspects of the problem being investigated[18]. At this stage, the judgment of the instrument must be based on the opinion of experts in the area, who suggest the addition and/or retention of items[19]. In this study, the Delphi method was chosen, which aims to obtain consensus among expert judges[20] for the validation of the instrument's content.

In choosing the judges, a non-probabilistic, snowball-type sampling was used, which enables the selection of people with similar profiles and who meet the interest of the study in question. Thus, the first judge was asked to appoint a second judge with a similar profile, and this in turn appointed a third judge following the same process and totaling five judges. The following criteria for the profile of specialists were considered: academic training in the area of health; title of doctor and/or master in the area; experience in teaching or assistance in the area; scientific production in the area and participation in a research group, such information was obtained through access to curricula available in the *Lattes* platform. The five judges were contacted via e-mail and received material for validation consisting of an invitation letter, informed consent form and validation form, with a pre-established deadline for return.

The form sent to the judges was subdivided into two parts: instrument content validation, in which categories and variables were judged for their relevance with the answers "yes" or "no" and a field for "suggestions" for new variables and/or categories. The second part of the form was composed of questions answered by Likert scale about the dimensions of the instrument related to clarity, thoroughness, relevance, the importance of the instrument, its implementation in services, sufficiency of variables and creation of a database. From the information collected, Cronbach's Alpha was calculated, and a written opinion on the quality and relevance of the instrument was requested.

After the first round of evaluation of the first version, which took place from October 2014 to December 2014, the judges suggested changes in structure (organization and presentation of the instrument) and in content (additions/exclusion of variables). All suggestions were consolidated and analyzed, confronted with the purpose of the study and, after adopting the pertinent suggestions, the intermediate version of the instrument was obtained, with which the pilot test was started.

The pilot test was carried out with twenty caregivers of children and adolescents with CI from June to July 2015. These caregivers were selected by consulting the admission book of the wards in three reference hospitals in the treatment of CI. The inclusion criteria for caregivers were: being the main caregiver, having clarity and understanding about the chronic illness, communication skills and reading and signing the free and informed consent form. In the pilot test, the saturation of adjustments and modifications in the instrument was used, based on the caregivers' suggestions, so that after this process, the instrument formed its second version.

The second evaluation carried out by the judges was took place between October 2015 and January 2016. At the time, the two versions of the instrument were sent: the first and the second version. With the results of the validation, the percentage of agreement between expert judges was analyzed for each of the variables.

The percentage of agreement is the method used to calculate agreement among judges. It is the simplest measure of agreement between raters and the most recommended in the initial phase of determining variables[21]. There is a recommendation for an agreement rate of 80 to 90% among judges[13,14]. The percentage of agreement is the division of the number of judges who agreed with the inclusion of the variable by the total number of participating judges, with the result being multiplied by 100 to be represented as a percentage. In this study, the cutoff point of 80% was adopted for acceptance of the variables.

To calculate the Cronbach's Alpha measure, the Likert scale points assigned by each judge for the instrument’s dimensions were used, and its result considered values above 0.70, which indicate satisfactory internal consistency for new instruments[14].

The content of the opinion issued by the judges was used to verify the quality and relevance of the instrument, and for the analysis of these texts, content analysis was used as a reference[22].

The research was approved by the Research Ethics Committee of the Universidade Federal da Paraíba, under Opinion No. 731.578/2014 and issuance of the Certificate of Presentation for Ethical Appreciation (CAAE) 33749714.3.0000.5183, which followed the norms of Resolution 466/2012 of the National Council Health Ministry of Brazil, involving human beings.

RESULTS

The data obtained in the validation process of the proposed instrument were presented as follows: profile of experts; description of variables and percentage of agreement of the judges in the first and second versions.

Five judges participated, four of whom were female and had been trained in public universities. As for the operating region, three worked in the Northeastern region, one in the Southeastern region and one in the Southern region of the country. The average years of experience in the area was 15.4 years, and the average scientific production in the area in the last 10 years was 28 studies published per year.

The content validation process of the first and last version of the instrument consisted of the variables that made up the first version of the instrument, two were excluded, 20 were modified, 72 were not changed, and 37 new variables were included as detailed in Table 1. Thus, the final version approved by 100% judges reached a Cronbach Alpha of 0.89. Table 1 presents the first and second versions.

Chart 1. First and second version of the Instrument for the Registration of Children and Adolescents with Chronic Illness, João Pessoa, 2016.

Category 1: Child or adolescent identification data		
First version	**Agreement among judges %**	**Second version**
1. Full name	100.0	1. No change
2. Gender	100.0	2. No change
3. SUS identification number	100.0	3. No change
4. Race/color	80.0	4. No change
5. Age	100.0	5. Age and birth date
6. Mother's full name	80.0	6. No change
7. Mother's birth date	100.0	7. No change
8. City of birth	100.0	8. No change
9. State	100.0	9. No change
10. City of current residence	100.0	10. No change
11. Address	100.0	11. No change
12. House number	100.0	12. No change
13. Address complement	100.0	13. Address complement/reference point
14. Neighborhood	100.0	14. No change
14. State	100.0	15. No change
15. Mobile phone number	100.0	16. No change
16. Home phone number	100.0	17. No change
18. Religion/belief	100.0	19. No change
19. Frequency at school	80.0	20. No change
20. Highest educational level	100.0	21. No change
21. Disability	80.0	22. No change
22. Marital status*	80.0	23. No change
23. Have any children*	100.0	24. No change
24. Employment status*	100.0	25. No change
25. Alcohol use*	80.0	26. No change
26. Tobacco use*	80.0	27. No change
27. Drug use*	80.0	28. No change
Second version	**Agreement among judges %**	
28. Inclusion: Type of school	100.0	
29. Inclusion: Full years of education	100.0	
30. Inclusion: Was there school failure	100.0	
1.1 Subcategory: Main caretaker data		
Second version		**Agreement among judges %**
31. Inclusion: Full name		100.0
32. Inclusion: Gender		100.0
33. Inclusion: SUS identification numbrt		100.0
34. Inclusion: Race/color		100.0
35. Inclusion: Age		100.0
36 Inclusion: Birthdate		100.0
37. Inclusion: City of birth		100.0
38. Inclusion: State		100.0
39. Inclusion: City of current residence		80.0
40. Inclusion: Reason for moving		80.0
41. Inclusion: Address		80.0
42. Inclusion: House number		80.0
43. Inclusion: Address complement/reference point		80.0
44. Inclusion: Mobile phone number		80.0
45. Inclusion: House phone number		80.0
46. Inclusion: Religion/belief		100.0
47. Inclusion: Marital status		100.0
48. Inclusion: Number of children/ages		100.0
49. Inclusion: Employment status		100.0
50. Inclusion: Highest educational level		100.0
51. Inclusion: Years of education		100.0
52. Inclusion: Alcohol use		100.0
53. Inclusion: Tobacco use		100.0
54. Inclusion: Drug use		100.0
55. Inclusion: Suffers from any illness		100.0
56. Inclusion: Takes any medication		100.0
Category 2: Sanitary and social data		
First version	**Agreement among judges %**	**Second version**
57. Housing situation/land ownership	80.0	58. No change
58. Localization	80.0	58. No change
59. Type of housing	80.0	59. No change
60. Predominant material in exterior wall coating	60.0	60. Excluded

61. Number of rooms	100.0	61. No change
62. Number of residents	100.0	62. No change
63. Presence of pets	100.0	63. No change
64. Water supply	100.0	64. No change
65. Driking water treatment	100.0	65. No change
66. Waste destination	100.0	66. No change
67. Human waste destination (feces/urine)	100.0	67. No change
68. Means of communication	100.0	68. Means of communication and transport
69. Have private healthcare	80.0	69. No change
70. Beneficiary(ies) of the private health plan	80.0	70. No change
71. Occurrence of chronic diseases in the family	80.0	71. No change
72. Relationship degree of the family member with chronic illness with the child/adolescent	80.0	72. No change
73.Level of kinship among parents of child/adolescent	80.0	73. No change
74.Family registered in government social programs	80.0	74. No change
75.Total family income	80.0	75. No change
Category 3: Illness and treatment data		
First version	**Agreement among judges %**	**Second version**
76.Final diagnosis	80.0	76. No change
77.Date of diagnosis	100.0	77. Date of definitive diagnosis and place responsible
78.Current stage of illness	100.0	78. No change
Subcategory: Data from the first search for the service to the definitive diagnosis		
First version	**Agreement among judges %**	**Second version**
79. First perceived signs	100.0	79. No change
80.First perceived symptoms	100.0	Group 79. First signs and symptons suggestive of a health issue and year
81.Which service or location you looked for first	100.0	81. No change
82. Means of transport used	60.0	82. No change
83. Reason that led to the search for the service/location	100.0	83. No change
84.Profissional who assisted the child/adolescent	100.0	84. No change
85. On-site exams were carried out	100.0	85. No change
86. Diagnostic hypothesis(ies)	100.0	86. First diagnostic hyptesis
87. A referral took place	80.0	87. Was there referal to another service
88. Has other associated illness(es)	80.0	88. No change
89.Service/place responsible for diagnosing the associated illness	100.0	89. No change
90.Uses another service/location to manage the associated illness	100.0	90. No change
91.Current length of hospital stay	100.0	91. Date of entry into current hospitalization
92.Main caregiver	80.0	92. Excluded
93.Current drug treatment	100.0	93. Current drug treatment and detail main drugs
94.Form of access to current medication	100.0	94. No change
95.Restrictions due to diagnosis	100.0	95. Restrictions due to diagnosis, detail food restriction and form of access
96.Dependent on the caregiver's general care	100.0	96. No change
97.Dependent on complex care	100.0	97. No change
Second version		**Agreement among judges %**
98.Inclusion: Outpatient consultation		100.0
99.Inclusion: Hospital stay days		100.0
100.Inclusion: Average annual hospitalization		100.0
101.Inclusion: Reason for current admission		100.0
102.Inclusion: Received information about the illness		100.0
103.Inclusion: Informant professional		100.0
104.Inclusion: The child/adolescent performs self-care		100.0
First version	**Agreement among judges %**	**Second version**
105. Palliative care	80.0	105. No change
106.Has sequelae or permanent damage as a result of illness	100.0	106. No change
107. Access to rehabilitation	100.0	108. No change
108. Service/place that performs rehabilitation	100.0	109. No change
109.What led to the choice/search for rehabilitation service/place	100.0	109. No change
Category 4: Service network data		
First version	**Agreement among judges %**	**Second version**
110.There is a reference Family Health team (FHS)	100.0	110. No change

110. Frequency using the service	100.0	111. Having an ESF, how often do you use the service to care for the child/adolescent
112.Has a clinic or specilized reference service	100.0	112. No change
113. Frequency using the service	100.0	113. Having a clinic or specialized service, how often do you use the service to care for the child/adolescent
114.Has a reference hospital	100.0	114. No change
115.Frequency using the service	100.0	115. Having a referral hospital, how often do you use the service to care for the child/adolescent
116.Look for a folk healer	80.0	116. No change
117.Frequency using the service	100.0	117. Frequency using the service to care for the child/adolescent
118. Look for faith healer	80.0	118. No change
119.Frequency using the service	80.0	119. Frequency using the service to care for the child/adolescent
120.Other services or places accessed for treatment of the illness	60.0	120. No change
121.Frequency using the service	100.0	121. Frequency using the service to care for the child/adolescent
Second version	**Agreement among judges %**	
122. Inclusion: Which service you look for?	100.0	
Category 5: Family dinamic data		
First version	**Agreement among judges %**	**Second version**
123.Involvement of other family members in care	100.0	123. No change
124.Activity performed	100.0	124. No change
125.Which member(s) perform it	100.0	125. No change
126.Feelings present currently	100.0	126. No change
127.The family receives some support	100.0	127. No change
128.Source of support received	100.0	128. No change
129.Family separation/segregation after the disease	100.0	129. Family relationship after the disease: Separation
130.Family union after the onset of the disease	100.0	130. Included as a sub-item of variable 129
131.Family limitation after the onset of the disease	100.0	131. Changes in family routine after the onset of the disease

* Variable specific to adolescent.

In the validation process, the judges issued an opinion on the instrument's attributes, which were organized and grouped into: *Highlighting the positive aspects of the instrument* and *Limitations presented by the instrument*, each judge was identified as “J” accompanied by a number 1-5.

Highlighting the positive aspects of the instrument

Highly relevant instrument with the proposed objective, being very comprehensive in relation to all the information that needs to be clear in the monitoring of children and adolescents with chronic illness [...]. *In addition, the creation of an instrument can be great as a trigger for other states to also adopt this strategy. A well-structured instrument that encompasses sociocultural and pathology-related aspects, but also investigates the support network and services accessed by this population, in addition to aspects of family functioning. The quality of this instrument is evident because it is complete and does not focus on just biological aspects or directed only at being sick.* [...] *It provides the health team with relevant information that can better guide the care of the child/adolescent and their family.* [J1]

[...] *I believe that the instrument and database will bring an enormous benefit to the services and to the state, in terms of monitoring the user of chronic childhood illnesses networks. It is an instrument for the development of a database for longitudinal studies, follow-up and assessment of quality of life, the influence of factors that may be determinant for this quality of life in addition to health issues.* [J2]

It is relevant, perhaps the 1st step to start giving visibility to this population, especially in PHC. This instrument is fundamental for the attention of these families and children [...] *to take care of them, is necessary to know the population and their demands. The instrument can lead to this.* [J3]

A relevant instrument in view of the lack of data for monitoring children and adolescents with chronic illness. [...] *An instrument of fundamental importance for the improvement of health care for children and adolescents with chronic illness* [...] *it represents a qualitative advance in the care of children/adolescents with chronic illnesses, given the gaps in monitoring of this group in the SUS health care network.* [J4]

The instrument demonstrates coherence and brings important characteristics for the identification and characterization of chronic patients. I see it as a script that could be used even in carrying out the anamnesis/interview. The scarcity of data related to the subject is known, making it difficult to monitor these children and adolescents [...] *it is essential to develop investigations to trace the profile of these children, adolescents and their* *families, in addition to understanding the difficulties and needs of health and care that these population deal with in everyday life. Who knows, in the future the instrument could also be discussed with local professionals to investigate the feasibility of being an official document adopted by all services. It is consistent among variables, sequential and can be an important instrument for recording information in a database for studies on the subject, as well as data for local and regional managers on the health condition of children/adolescents and those with chronic illnesses. It is important to standardize the collection of information and create a database of users with chronic illness in childhood and adolescence. The instrument can collaborate with the planning of specific health actions for children/adolescents and families living with chronic illnesses and subsidize a database to identify the panorama and profile of these users and what the health needs of this group are. It can also contribute to the development of a program/line of care for users with chronic diseases in childhood/adolescence. Perhaps for the research, the instrument will bring numerous results to support the planning and proposition of health actions for children with chronic illnesses.* [J5]

Limitations presented by the instrument

It is only necessary to be aware that the size of the instrument may be a future complicating factor for this information to continue to be collected, preventing the continuation of this work, which is so relevant in the care of children and adolescents in the state. [J1]

[...] *it is an interesting instrument for a database, however if it is digitalized and interconnected, or if it is for use with a tablet, because monitoring a patient during consultation, filling out the regular form is tiring.* [...] *there could be more data that allow longitudinal studies* [...] *the variables are enough to register, however, if more detailed clinical follow-up is needed, it is necessary to go to the medical record.* [J2]

[...] *it lacked to include aspects of spirituality, as in general it is faith that keeps these families with energy to face daily life* [...] *thinking of a digitalized network integrated in the 3 levels of care, it would be highly effective, but if not, where will it be applied and filed?* [J3]

I still think the instrument is very extensive for the registration of health professionals, considering all the daily difficulties of high demand. [J5]

DISCUSSION

There were no productions about an instrument with a purpose close to or similar to the content and validated in this study, which somehow made the discussion about the relevance of the variables that made up the instrument unfeasible.

In the analysis of the first version of the instrument, the specialists requested the change of variables in the first category: 5 - addition of the date of birth; and 13 - addition of a reference point, and the specification that variables 22-27 should be answered by the adolescents. They also suggested the creation of a subcategory for the caregiver with variables that could identify and characterize them, such as variables were validated in the second Dephi round and obtained the acceptable percentage of agreement.

During the pilot test, after analyzing the first version, the caregivers suggested the inclusion of three variables: 28 - type of school; 55 - suffers from any illness; 56 - takes any medication, these variables emerged in view of the need reported by caregivers in the collection of pilot data and were validated in the second Delphi round.

In the second category, the variable 60 - predominant material in the exterior wall coating was excluded, as it did not reach the established percentage of agreement. The variable 68 - means of communication also included the means of transport used by the family. All suggestions were accepted and, during the instrument's pilot test, there were no changes in content/structure in this category.

The analysis of the third category by the judges resulted in structural and content changes of the instrument was the category that contemplated the therapeutic itinerary of the child/adolescent and their families, portraying the search for the diagnosis of the disease, the health services accessed, in addition to the health professionals included in the process.

The structural change suggested by the judges was the exclusion of the subdivisions of the chronic disease phases, namely: initial, chronic and terminal/final phase, under the justification of continuous repetition of the variables already mentioned in the initial phase 75-93 that could compromise the completion of the instrument, making it long and unfeasible to use. The suggestion was to create two subsections, “Data from the first search for the health service until the definitive diagnosis" and "Data from the outpatient visit/current hospitalization", grouping the variables in order to optimize the registration, time and length of the form.

Changes were made to variable 77 - of the place responsible for the definitive diagnosis at the request of the caregivers during the pilot test. Variables 79 and 80 were grouped; variable 87 was changed to indicate the family's search for a second service, and the judges pointed out the need to repeat variables 83, 84 and 85, with some variations, at various points in the instrument to refer to all services sought by the family and how it was attended to in these places.

Still in compliance with the judges' requests, variable 91 - was changed to date of entry into current hospitalization, and variable 93 - was requested to detail the medications used. In the pilot test, caregivers asked for details, in case of food restriction, on the form of family access to food and the inclusion of information received from professionals about the disease, which constituted variables 95 and 102. Also, were included changes in variables 98 to 101 and 104 in the first round and all inclusions and alterations were validated in the second Delphi round, obtaining a percentage of agreement favorable to their permanence in the instrument.

In the fourth category that included the network of services accessed by the family, variable 120 "other services or places accessed for the treatment of the illness" had a low percentage of agreement in the first version, however it was clarified to the judges that this variable is important to contemplate other locations, in addition to the FHU, clinic, hospital, folk healer and faith healer that make up the family network, and in the second round the variable was accepted.

The suggestions for changing the content of the first round aimed to qualify the frequency that the family sought each service, thus changing variables 111,113, 115, 117 and 119, in addition to repeating variables 102 and 103 to obtain data on information provided by professionals in each service searched, therefore, variable 122 was also included on which was the reference professional in the service accessed.

The judges also suggested grouping variables 'folk healer' with 'faith healer', however, during the pilot, caregivers reported that these have different popular functions and meanings and, under this justification, these questions remained separate in the final version. All inclusions were evaluated in the latest version and received acceptance. In the last assessment there were no suggestions for changes by the experts.

In the fifth category, which deals with family dynamics, the judges asked to change the variable 129 and inclusion of variable 130 as a sub-item, and in variable 131, the replacement of the term "family limitations" by "changes in family routine", as these could induce the caregiver at the time of collection.

At the end of the analysis by judges and participation of caregivers, all pertinent observations were considered (exclusions, insertions) so that the final version of the instrument consisted of 131 numbered variables, and the numerical order of the variables described in the results was reorganized.

A study[23] points out that it is essential for the researcher to be inserted in the social context of the target population, knowing their needs and particularities, thus, the importance of the participation of caregivers in the validation phase of the instrument is highlighted.

The need to better understand the health problem in order to organize and plan care was highlighted by expert judges. It was observed that the categories that made up the instrument can expand knowledge about the interactions between the child/adolescent and their family, with the service network, as well as its implications for family dynamics.

In this sense, the use of the instrument in question to start the process of developing information technology in the area of child and adolescent health and envisioning possibilities for its implementation in health services with a view to improving the management of care can be promising. This work shows that nurses' contribution to optimizing the quality of services and care in the context of chronic diseases is important, both for their critical-reflective capacity and for decision-making, as a member of the multidisciplinary teams that provide direct care to the population in question[24]. Thus, the use of the instrument validated by other professionals is recommended.

Despite having been developed to be applied at the time of hospitalization, the use of the instrument in primary health care is a plausible possibility as long as new variables that better portray the contact of these families with this point of the network are added. PHC occupies a place of importance and protagonism in the care process for children and adolescents with chronic illnesses and their families, as it is the closest point of care and with viable access.

The way in which PHC is organized still hinders the operationalization of the adequate care model for chronic health conditions, as it must be supported by several elements, including evidence-based clinical guidelines, user identification system, registration of people with health conditions due to risks, use of electronic medical records with warning and feedback systems[25].

In the context of information technology, the use of the instrument presented served as the basis for the development of a database, and was incorporated into the development of a software called *Sistema de Informação de Crianças e Adolescentes com Doença Crônica* - SICADC (Information System for Children and Adolescents with Chronic Illnes) to provide access direct information to support decision-making[16].

The inclusion of the family as the focus of care and not only as a source of information should be seen by professionals from different levels of care as a challenge to be overcome in order to improve the quality of life of those involved[4,5,10].

CONCLUSION

This study described the construction and validation of an instrument for the registration of children and adolescents with chronic illness, and this can be used by other health services that provide health care to the public in question in other locations.

Given the size of the instrument, possible difficulties may occur by professionals who provide direct assistance to children, adolescents and their families. In turn, the constructed and validated instrument can serve as a starting point for the creation of other specific instruments that allow longitudinal follow-up and clinical evolution of specific diseases.

As a limitation of the study, there is the lack of international and even national references about the registration in health services for children and adolescents in CI; on the other hand, the instrument fulfills both the registration need and can serve as a material that favors research and care work.

REFERENCES

1. Separavich MA. [review]. Tessituras do cuidado: as condições crônicas de saúde na infância e adolescência. Ciênc Saúde Colet. [Internet]. 2018 [cited in 08 July 2020]; 23(2):671-2. DOI: http://dx.doi.org/10.1590/1413-81232018232.20842017

2. Xavier DM, Gomes GC, Cezar-Vaz MR. Meanings assigned by families about children's chronic disease diagnosis. Rev Bras Enferm. [Internet]. 2020 [cited in 16 Aug 2020]; 73(2): e20180742. DOI: https://doi.org/10.1590/0034-7167-2018-0742

3. Souza MHN, Nóbrega VM, Collet N. Social network of children with cronic disease: knowledge and practice of nursing. Rev Bras Enferm. [Internet]. 2020 [cited in 16 Aug 2020]; 73(2): e20180371. DOI: http://dx.doi.org/10.1590/0034-7167-2018-0371

4. Araújo YB, Santos SR, Neves NTAT, Cardoso ELS, Nascimento JA. Predictive model of hospitalization for children and adolescents with chronic disease. Rev Bras Enferm. [Internet]. 2020 [cited in 08 July 2020]; 73(2):e20180467. DOI: http://dx.doi.org/10.1590/0034-7167-2018-0467

5. Lopes ACC, Nóbrega VM, Santos MM, Batista AFMB, Ramalho ELR, Collet N. Cuidado à saúde nas doenças crônicas infanto-juvenis. REFACS [Internet]. 2020 [cited in 19 Aug 2020]; 8(Supl 2):674-84. DOI:10.18554/refacs.v8i0.4286

6. Malta DC, Bernal RTI, Guimarães LM, Araújo SSC, Silva MMA, Freitas MIF, et al. Noncommunicable diseases and the use of health services: analysis of the National Health Survey in Brazil. Rev Saúde Pública [Internet]. 2017 [cited in 11 Dec 2020]; 51(Suppl1):4s. DOI: https://doi.org/10.1590/S1518-8787.2017051000090

7. Xavier TGM, Araújo YB, Reichert APS, Collet N. Classe hospitalar: produção do conhecimento em saúde e educação. Rev Bras Educ Espec. [Internet]. 2013 [cited in 24 Sep 2021]; 19(4):611-22. Available from: https://www.scielo.br/j/rbee/a/h8TBkXNBxskRLbkcZJGgr7D/?format=pdf&lang=pt

8. Holanda ER, Collet N. As dificuldades da escolarização da criança com doença crônica no contexto hospitalar. Rev Escola Enferm USP [Internet]. 2011 [cited in 24 Sep 2021]; 45(2):381-9. DOI: https://doi.org/10.1590/S0080-62342011000200012

9. Reis RS. A influência dos determinantes sociais na saúde da criança. Libertas [Internet]. 2005 [cited in 24 Sep 2021]; 4(Esp):17-42. Available from: https://periodicos.ufjf.br/index.php/libertas/article/view/18131

10. Zamberlan CK, Neves ET, Severo VRG, Santos RP. The care of the child with chronic or disabling disease in the hospital context. J Res Fundam Care Online [Internet]. 2014 [cited in 20 July 2020]; 6(3):1288-301. DOI:10.9789/2175-5361.2014v6n3p1288

11. Moreira MTM, Pinheiro JAM, Florêncio RS, Cestari VRF, organizadoras. Tecnologias para a promoção e o cuidado em saúde. Fortaleza: EdUECE; 2018. 387p. Available from: http://uece.br/eduece/dmdocuments/TECNOLOGIAS_PARA_A_PROMOCAO_E_O_CUIDADO_EM_SAUDE.pdf

12. Agra G, Formiga NS, Oliveira SHS, Sousa ATO, Soares MJGO, Lopes MM. Instrument Validation on nurses' knowledge and practice in palliative care for people with cutaneous malignant tumor wound. Aquichan [Internet]. 2020 [cited in 18 July 2020]; 20(1):e2012. DOI: https://doi.org/10.5294/aqui.2020.20.1.2

13. Pasquali L. Psicometria: teoria dos testes na psicologia e na educação. Petrópolis, RJ: Vozes; 2017.

14. Polit DF, Beck CT. Fundamentos de pesquisa em enfermagem: avaliação de evidências para a prática da enfermagem. 9ed. São Paulo: Artmed Editora; 2018.

15. Araújo YB, Santos SR, Bezerra TA, Lima DM, Mello MN, Neves NTAT, et al. Validated instruments for children and adolescents with chronic disease: an integrative review. Int Arch Med. [Internet]. 2016 [cited in 1 July 2020]; 9(92):1-9. DOI: http://dx.doi.org/10.3823/1963

16. Araújo YB. Sistema de Informação de Crianças e Adolescentes com Doença Crônica (SICADC): uma ferramenta de apoio à decisão. [Internet]. [dissertation]. João Pessoa: Universidade Federal da Paraíba. 2017 [cited in 12 July 2020]. 186p. Available from: https://sig-arq.ufpb.br/arquivos/20171880885bd5473637d5d086e8753c/TESE_YANA_BAUDUINO_DE_ARAUJO.pdf

17. Souza AC, Alexandre NMC, Guirardello EB. Psychometric properties in instruments evaluation of reliability and validity. Epidemiol Serv Saúde [Internet] 2017 [cited in 9 July 2020]; 26(3):649-59. DOI: 10.5123/S1679-49742017000300022

18. Siqueira JP, Guimarães EAA, Oliveira VJ, Gontijo TL, Quites HFO, Amaral GG, et al. Conhecimento dos profissionais de saúde acerca da vacinação em gestantes: construção e validação de conteúdo de um instrumento. Rev Cuid. [Internet]. 2020 [cited in 10 Aug 2020]; 11(1): e872. DOI: https://doi.org/10.15649/cuidarte.872

19. Pinheiro DGM, Coelho TPB, Silva CFA, Silva LA, Chiesa AM, Fracolli LA. Content validation of a home visit program for mothers and children. Cogitare Enferm. [Internet]. 2018 [cited in 29 July 2020]; (23)2:e54055. DOI: http://dx.doi.org/10.5380/ce.v23i2.54055

20. Revorêdo LS, Maia RS, Torres GV, Maia EMC. O uso da técnica Delphi em saúde: uma revisão integrativa de estudos brasileiros. Arq Ciênc Saúde [Internet]. 2015 [cited in 20 July 2017]; 22(2):16-21. DOI: https://doi.org/10.17696/2318-3691.22.2.2015.136

21. Hulley SB. Delineando a pesquisa clínica. 4ed. Porto Alegre: Artmed; 2019. 386p.
22. Bardin L. Análise de conteúdo. 70ed. Lisboa, Portugal: Edições; 2009.
23. Leite SS, Áfio ACE, Carvalho LV, Silva JM, Almeida PC, Pagliuca LMF. Construction and validation of an Educational Content Validation Instrument in Health. Rev Bras Enferm. [Internet]. 2018; 71(Suppl4):1635-41. [Thematic Issue: Education and teaching in Nursing]. DOI: http://dx.doi.org/10.1590/0034-7167-2017-0648
24. Gallani MCBJ. O enfermeiro no contexto das doenças crônicas. Rev Latinoam Enferm. [Internet]. 2015 [cited in 24 Sep 2021]; 23(1):1-2. DOI: 10.1590/0104-1169.0000.2517
25. Duarte EL, Silva KLT, Tavares TS, Nishimoto CLJ, Silva PM, Sena RR. Cuidado à criança em condição crônica na atenção primária: desafios do modelo de atenção à saúde. Texto & Contexto Enferm. [Internet]. 2015 [cited in 11 Dec 2020]; 24(4):1009-17. DOI: http://dx.doi.org/10.1590/0104-07072015000003040014

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