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EDUCATIONAL FOLDER FOR CAREGIVERS OF CHILDREN WITH HIV/AIDS

FOLDER EDUCATIVO PARA CUIDADORES DE CRIANÇAS COM HIV/AIDS

FOLLETO EDUCATIVO PARA CUIDADORES DE NIÑOS CON VIH / SIDA

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ABSTRACT

Objective: to construct an educational technology for caregivers of children with HIV / AIDS. **Method:** this is a quantitative study, methodological type, made from the construction of educational material, with subsequent validation by nine judges and evaluation of 15 caregivers. Content validation was established from the Content Validity Index with concordance equal to or greater than 0.78. **Results:** the folder was composed of eight pages and based on literature and interviews with caregivers to capture part of their subjectivity about the perception and expectation that permeate the care of children with HIV / AIDS. The items were assessed as adequate to reach the total IVC of 0.90. It was evidenced that the percentage of agreement of the caregivers was of 100% in the majority of the items. **Conclusion:** the folder was constructed and validated, and it can be used in health education with caregivers, providing the empowerment to care for children with HIV / AIDS. **Descriptors:** Caregivers; Child; HIV; Technology; Health Education; AIDS Serodiagnosis.

RESUMO

Objetivo: construir uma tecnologia educativa para cuidadores de crianças com HIV/AIDS. **Método:** trata-se de estudo quantitativo, tipo metodológico, realizado a partir da construção do material educativo, com posterior validação por nove juízes e avaliação de 15 cuidadores. Estabeleceu-se a validação de conteúdo a partir do Índice de Validade de Conteúdo com concordância igual ou maior que 0,78. **Resultados:** compôs-se o folder por oito páginas e embasaram-se os seus textos na literatura e em entrevistas realizadas com cuidadores para apreender parte da subjetividade destes sobre a percepção e a expectativa que permeiam os cuidados à criança com HIV/Aids. Avaliaram-se os itens como adequados alcançando o IVC total de 0,90. Evidenciou-se que o percentual de concordância dos cuidadores foi de 100% na maioria dos itens. **Conclusão:** construiu-se e validou-se o folder podendo este ser utilizado na educação em saúde com cuidadores proporcionando o empoderamento ao cuidado de crianças com HIV/Aids. **Descritores:** Cuidadores; Criança; HIV; Tecnologia; Educação em Saúde; Sorodiagnóstico da AIDS.

RESUMEN

Objetivo: construir una tecnología educativa para cuidadores de niños con VIH / SIDA. **Método:** se trata de estudio cuantitativo, tipo metodológico, realizado a partir de la construcción del material educativo, con posterior validación por nueve jueces y evaluación de 15 cuidadores. Se estableció la validación de contenido a partir del Índice de Validez de Contenido con concordancia igual o mayor que 0,78. **Resultados:** se compuso el folleto por ocho páginas y basaron sus textos en la literatura y en entrevistas realizadas con cuidadores para aprehender parte de la subjetividad de éstos sobre la percepción y la expectativa que permean los cuidados al niño con VIH / SIDA. Se evaluaron los ítems como adecuados alcanzando el IVC total de 0,90. Se evidenció que el porcentaje de concordancia de los cuidadores fue del 100% en la mayoría de los ítems. **Conclusión:** se construyó y validó el folleto pudiendo este ser utilizado en la educación en salud con cuidadores proporcionando el empoderamiento al cuidado de niños con VIH / SIDA. **Descriptores:** Cuidadores; Niño; VIH; Tecnología; Educación en Salud; Serodiagnóstico del SIDA.

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INTRODUCTION

It is known that the progression of acquired immunodeficiency syndrome (AIDS) as an epidemic has reached the child population.¹ The syndrome is also associated with stigma and marginalization, mainly referred to by people living with HIV. It is perceived that the fear of prejudice or discrimination causes people living with HIV / AIDS to hide their serological condition and limit their possibilities of rights and health care.

It is understood that feelings such as fear and guilt arise in the face of seropositivity and the threat that this infection can generate in the child causes apprehension and anxiety in caregivers.²

It is revealed that, according to estimates by the Joint United Nations Program on HIV and AIDS, there are 35.3 million people living with HIV / AIDS in all continents of the world and, of these, 3.3 million are children under 15 years of age. In 2012, new infections were registered, accounting for 2.3 million cases of which 260,000 were children. It is added that, in the same year, there were 1.6 million AIDS deaths, of which 210,000 were under 15 years of age.³

It is considered, according to current national guidelines, that the definition of AIDS case in children for epidemiological surveillance purposes is any individual under the age of thirteen who presents laboratory evidence of HIV infection and some evidence of immunodeficiency.⁴

It is emphasized that childcare is a universal practice, but special care is needed for children living with HIV, as most caregivers need to be assisted in the care of the child. The low level of knowledge of caregivers on HIV prevention and pediatric care is revealed in studies and it is suggested that caregiver-based awareness programs need to be strengthened in order to improve acceptance of caregiver diagnosis and care early HIV.

It is evidenced that the family suffers when it perceives the incurable diagnosis of the child, mainly, for having difficulty in dealing with this reality. The caregiver becomes familiar with the uncertainty, the insecurity, the disorder and the continuous need for reorganization, since the family is the basic unit in the construction and development of the individuals that compose it. Social and emotional support to these relatives is therefore essential, since they need guidelines to learn how to deal with the problem and to reorganize the family structure and coping strategies of the disease and its sequelae, according to their referents of culture.⁶

It is understood that, in the care process, attention should not be focused on pathology, but priority should be given to the promotion, maintenance and recovery of health.⁷ It is understood that the child with HIV / AIDS needs to live with the disease and can go through difficult situations and confused understanding needing special care of their family caregiver. It is added that, in this sense, this needs to be properly instrumentalized for effective coping with everyday situations and moments of guilt, shame, among other negative feelings, can interfere both in their daily life and in the care given to their children.⁸

It is recalled that the family / caregiver is directly involved in the health-disease process of the child using antiretroviral therapy. It is necessary to constantly monitor the practice of caring accompanied and supported by the health team so that adequate interventions are developed for the improvement of the home care.

It is noted that practices in health education and the provision of educational materials are effective interventions that improve care for children with HIV / AIDS, and educational technology is an effective strategy to truly involve caregivers in monitoring their children improving consequently, its general state, favoring the control of the disease and the prevention of complications such as opportunistic diseases. Educational technologies are intended to contribute to teaching-learning activities and to mediate educational practices in the community and / or with specific types of users.⁹

Based on the above, the following guiding questions are addressed: How does the family care for the child with HIV/AIDS? What are the difficulties and facilities related to the care of children with HIV/AIDS?

It is believed that educational technology will contribute to the adequate and safe development of home care, stimulating the subjects to reflect on their knowledge and practices of the HIV-positive child and preventing future complications.

OBJECTIVES

- To build an educational technology for caregivers of children with HIV / AIDS.
- To validate educational technology for caregivers of children with HIV / AIDS.

METHOD

This is a quantitative study, methodological type carried out from the construction of an

educational folder with subsequent validation by judges and evaluation of the target audience and developed in a hospital of reference in infectious diseases located in the city of Fortaleza-CE.

The guidelines in compliance with the legislation on research involving human beings, Num. 466/12, were respected and this research was authorized by the scenario institution of the study and approved by the Committee of Ethics in Research of Hospital São José under the opinion number 1,881,805 and CAAE 62595816.1.0000.5044. For the data collection, the Confidentiality Term was used, which ensures the commitment to maintain the confidentiality of the data, signed by the coordinator responsible for the research.

In order to base the educational material on the needs of its target audience, previous knowledge and the opinions of caregivers regarding the themes that should be included in the folder were investigated through a semi-structured interview, at the site of the research, in the period of January and February of 2017. A script that contained questions related to home care was used. It was suggested, through such a survey, that the folder contained information about the guidelines related to medication, side effects, prejudice and disclosure of the diagnosis.

Illustrations were selected that emphasized important ideas in the text avoiding unnecessary images or diverting the reader's attention to the central message. It facilitates, through the coherence between text and image, the memorization and retake of the information that is transmitted favoring its assimilation.¹⁰ The illustrations were created by a drawing specialist who used the Draw Essentials program and colored them in Adobe Photoshop.

At the end, the folder was composed of eight pages with three zigzag folds, so that the front and back of the sheet were used in their printed version and the folder was formatted to contain the guidelines and necessary for home care.

The following inclusion criteria were used in the content and appearance validation stage: professionals with a thesis/dissertation/specialization in the area of interest; participation in groups/research projects that involve the theme of the area of interest; have practical experience with HIV/AIDS and published works in the area of interest, as well as experience in the validation of educational materials.

The group was selected from June to July 2017, using the "snowball" method, by

indication or from the Lattes Platform, with the following keywords: assistance to children with HIV / AIDS; child health; Health education; validation of educational technology; home care After the selection of specialists, in person or by referral, 13 letters were invited. Results were sent invitations and contacts made in a final sample of nine specialists who integrated this research.

The Content Validity Index (CVI) method was used, which measures the proportion or percentage of judges who agree on certain aspects of the instrument and its items.¹¹ It is possible, through this method, to initially analyze each item individually and then the instrument as a whole. A Likert scale, with a score of one to four, was used to evaluate the representativeness of its use in the practice of home care. The items that obtained a concordance of at least $CVI \geq 0.78$.¹² The instrument was elaborated with 22 items, reaching a total CVI of 0.90.

After the validation of content and appearance and the conclusion of the adjustments suggested by the judges, the educational material was evaluated by the target public. Fifteen caregivers were invited to participate in the study from August to October 2017, respecting the following criteria: to be the main home caregiver / institutional of the child; be duly registered in the aforementioned service and know how to read and write.

Caregivers were excluded from patients who presented cognitive deficits due to the probable alteration of the discourse that these participants could present due to the emotional and socioeconomic issues that may interfere in the responses given to the researcher and those who presented a state of physical or mental health compromised to make the evaluation of the technology to be developed unfeasible. Individual caregivers were approached at the outpatient clinic of the referred institution while they waited for the monthly consultation.

It should be noted that, in the instrument used for the evaluation, the answers to the questions were presented with variables. For each variable, a score of zero (not suitable), one (adequate) or two (totally appropriate or superior) was assigned. It was asked for the options "zero" and "one" to describe the reason why the caregiver considered this option in a placeholder. The positive response was considered when the option "two".

At the end of the instrument, a space was allocated for the caregivers to write their personal opinions (in general, what did you

think of the educational material? What suggestions to improve the folder?).

The items that obtained a minimum agreement level of 75% in the positive responses were considered validated, according to the standard established by Teles.¹³ The items with agreement index less than 75% were considered as worthy of change.

The data collected in tables and graphs were organized and the analysis was carried out in order to identify the impact on the knowledge and practice regarding home care for these children.

RESULTS

As a criteria for inclusion, the literature on the topics related to the care of children with HIV / AIDS indexed in PubMed (Public / Publish Medline), SCIELO (Scientific Electronic Library Online) and LILACS (Latin- American and Caribbean in Health Sciences), with a temporal cut in the period from 2013 to 2017, totaling 12 articles.

It is known that, of the articles included in the analysis, five were produced in Africa, corresponding to 41.6%, and four were produced in Brazil, equivalent to 33.3%. It is noteworthy that six selected articles (50%) discussed the difficulty of the caregiver in revealing the diagnosis to the child either because of fear of discrimination, either because of the difficulty in approaching the subject or because he did not know the ideal time for the diagnosis to be revealed.

The results showed a low level of knowledge of caregivers about pediatric prevention and care emphasizing the need for

training of caregivers and thus improving the acceptance of early diagnosis and HIV care.⁵

It was revealed in another result found in this review that the family and the specialized service constitute the main social networks of the caregiver evidencing the need to strengthen this fragile network with a family-centered approach to qualifying and effecting care for the child.¹⁴

It was also highlighted the need to provide caregivers with the skills to recognize the timing of disclosure of the child's diagnosis as well as emotional and psychological support to manage it adequately.

It is noted that the interviews conducted to guide the content of the folder took approximately 15 to 25 minutes and participants answered questions about sociodemographic characteristics, as well as semi-structured issues related to home care.

The information contained in the folder was organized in such a way as to facilitate the logic of understanding, starting with the definitions, the necessary care to be carried out by the caregiver from medication administration, adherence to care of the child's personal hygiene, prejudice and ending with the support network.

It was decided to present the contents of the educational folder in seven topics with the following themes: HIV and opportunistic diseases; information on medications; Side effects; accession; child care routines; prejudice and support networks.

An instrument evaluating the folder regarding the objectives (Figure 1), structure and presentation (Figure 2) and relevance (Figure 3) was used, by the judges.

Figure 1. Evaluation of content judges regarding the objectives of the folder. Fortaleza (CE), Brazil, 2017.

It should be noted that the judges validated all the objectives of the folder objectives and the total CVI for this category was 0.87. However, in relation to item 1.6, which deals with the promotion of behavioral

change and attitudes, three specialists considered it as "partially disagree", which led to the item reaching a CVI of 0.66. They were asked to describe the reason why they considered this option so that the researcher

could adapt the folder in a more coherent and reasoned manner.

Note that judge six classified item 1.7 as "disagree" and, in his writing, justifies: "I understand that it is not intended for professionals, but for caregivers".

It is recalled that the judges also evaluated the folder in terms of structure and presentation, reaching the CVI of 0.94, according to figure 2.

Figure 2. Evaluation of content judges regarding the structure and presentation of the folder. Fortaleza (CE), Brazil, 2017.

It is indicated that none of the items was marked as "disagree". It is added, however, that Judge Four considered some items to be "partially disagree". The comments were analyzed and all the suggestions were taken into account and followed, as explained below:

- Item 2.2 - judge Four suggested adding "how one gets and how one does not get AIDS" as well as the inclusion of natural foods in the part related to the routine of care;
- Item 2.4 - judge four proposed that the item related to the adhesion be subsequent to the item related to the side effects following a sequence in the guidelines;

- Item 2.6 - judge four advised to summarize the information by reducing visual pollution;
- Item 2.8 - judge four recommended the inclusion of a cover, the punctuation at the end of some sentences as well as the accentuation that was lacking in the word "no";
- Item 2.9 - judge four suggested the change in the figure of the medical professional, who kept an unfriendly look.

The validation was finalized with this group of judges and will be seen, in figure 3, the evaluation that they made of the folder in relation to its relevance.

Figure 3. Evaluation of content judges regarding the relevance of the folder. Fortaleza (CE), Brazil, 2017.

Therefore, the validation of its appearance and content with specialists was ratified, since the global CVI of educational technology was 0.90, obtaining the appropriate concept. It is recalled that, as previously stated, if the folder was considered appropriate and valid at this stage, it would move to the next step.

It is noteworthy that the judges made several suggestions for the improvement of educational material. These suggestions were complied and compiled according to the folder domains. After the adaptation of the folder, the validation of the appearance with caregivers of children with HIV / AIDS was carried out.

Fifteen caregivers were taken at the research site, in the days of the outpatient clinic, of which 11 (73.33%) were mothers and four (26.66%) were other relatives, making a total of eight meetings. The number of participants was closed with data saturation.

It is evidenced that the caregivers responded to the instrument of evaluation of the educational material in which a percentage of agreement of 100% was obtained in the majority of the evaluated items, according to the degree of agreement, according to figure 4.

Figure 4. Degree of agreement of the evaluation items of the folder by the target public. Fortaleza (CE), Brazil, 2017.

It was observed, after reading the comments of the caregivers, that the items were considered positive, for the most part, although succinct. It was considered that this type of resource should be available in the health units by the caregivers who also stated that they would like to take it home emphasizing its importance for the explanation of doubts and the provision of guidelines.

It is also noticed the stigma that permeates the condition of being seropositive for HIV. It was also evidenced the need for psychological support and greater attention during

educational activities, since psychosocial factors are strongly present in relation to the acceptance of the infection, thus interfering in the care of the child.

It is known that, after validation with the target audience, it was necessary to return to the designer to make the necessary changes, which gave rise to the final version of the folder, according to figure 5, which describes part of the educational folder aimed at the caregivers.

Figure 5. Final version of the educational folder. Fortaleza (CE), Brazil, 2017.

CONCLUSION

It met the objective proposed by this study from the preparation and validation of the educational folder. It was also possible to know the difficulties and facilities of the family to care for the child with HIV/AIDS.

The main limitations were the confidentiality of the child's diagnosis, the administration of antiretroviral drugs to the child, financial issues and the occurrence of prejudices both by the people of the family and by other people. They referred, as to the family's facilities for care, easy access to health units, obtaining the benefit to those entitled and the support of family and friends.

The study folder was shown as validated material from the point of view of appearance and content since it presented a global CVI of 0.90, from the evaluation by the judges, and level of agreement from 93.33% to 100%, by the representatives of the target audience, and should therefore be assessed in the context of educational activities as an instrument capable of favoring information about home care.

In considering the limitations of this study, it is believed that the use of this material with caregivers of children with HIV/AIDS will contribute to coping with the infection as well as to help people and children with HIV rebuild their lives, improve coping skills, build local support networks, and increase access to available resources as necessary interventions to reduce HIV-related psychosocial distress among this population.

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