

Development and validation of a booklet for prevention of vertical HIV transmission

Construção e Validação de cartilha para prevenção da transmissão vertical do HIV

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Keywords

Infectious disease transmission, vertical; HIV; Teaching materials; Validation studies

Descritores

Transmissão vertical de doença infecciosa; HIV; Materiais de ensino; Estudos de validação

Submitted

December 27, 2016

Accepted

March 20, 2017

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DOI

<http://dx.doi.org/10.1590/1982-0194201700028>



Abstract

Objective: To describe the process of development and validation of an educational booklet for prevention of HIV - vertical transmission.

Method: A methodological study conducted in three stages: bibliographical survey, development of the booklet, and validation by specialists in the subject and representatives of the target audience. Nine experts and 30 representatives of the target audience performed the validation. A minimum Content Validity Index (CVI) of 0.78 was considered for content validation, and minimum agreement of 75% for face validation.

Results: The booklet presented a global CVI of 0.87. The level of agreement within the experts (91.1% -100%) and representatives of the target audience (98.1% -100%) was excellent. However, improvements in the booklet was proposed by the experts, which were accepted and modified for the final version of the material.

Conclusion: The booklet was validated using content and face validity. It can be considered an instrument to promote the prevention of vertical transmission of HIV, in the context of educational activities.

Resumo

Objetivo: Descrever processo de construção e validação de cartilha educativa para prevenção da transmissão vertical do HIV.

Método: Estudo metodológico em três etapas: levantamento bibliográfico, elaboração da cartilha e validação do material por especialistas no assunto e representantes do público-alvo. Realizou-se a validação por 9 juízes e 30 representantes do público-alvo. Considerou-se o Índice de Validade de Conteúdo (IVC) mínimo de 0,78, para validação de conteúdo e concordância mínima de 75% para validação de aparência.

Resultados: A cartilha apresentou IVC global de 0,87 pelos juízes e nível de concordância excelente entre os juízes (91,1%-100%) e representantes do público-alvo (98,1%-100%). Entretanto, os juízes propuseram sugestões de melhorias da cartilha, que foram acatadas e modificadas para versão final do material.

Conclusão: A cartilha foi validada quanto ao conteúdo e aparência, devendo-se ser considerada no contexto das atividades educativas como instrumento capaz de favorecer para prevenção da transmissão vertical do HIV.

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Conflicts of interest: there are no conflicts of interest to declare. Article from the Master's thesis, "Development and validation of an educational booklet for the prevention of vertical transmission of HIV", presented to the Graduate Program of the Universidade Federal do Ceará, Fortaleza, Fortaleza, CE, Brazil. The author was a scholar of the National Council for Scientific and Technological Development, Conselho Nacional de Desenvolvimento Científico e Tecnológico -CNPq, Brazil.

Introduction

The feminization of HIV includes among its aggravating factors the risk of increasing vertical transmission (VT). This is the main method of HIV infection in children under 13 years of age, in Brazil, with 99.6% of the cases; there was a vertical transmission rate of 7.5% in 2003 and 2004.

⁽¹⁾ Thus, The Ministry of Health (MH) determined a set of measures to be conducted in the prenatal, delivery and puerperium of seropositive women which, when implemented in their totality, reduce the rate of vertical HIV transmission (HIV-VT) to almost zero.^(1,2)

In addition to the high efficacy of prophylaxis for VT reduction, studies indicate several factors that make it more difficult: late diagnosis of infection during pregnancy; failure to provide counseling and guidance to every woman during prenatal care; the quality of care that remains below what is desired; lack of knowledge of the professionals; as well as lack of knowledge on the part of pregnant women regarding preventive measures.⁽³⁻⁶⁾

Lack of participatory and dialogic educational activities directed toward HIV positive pregnant women and mothers, by health professionals, associated with their lack of knowledge about HIV, negatively affect the vulnerability of the mother-child binomial. However, studies show that health education is an effective means for the prophylaxis of VT.⁽⁶⁾

Thus, when using a technology during nurses' educational practices in this area, a broad search was required to be made in the specialized databases, yet no publications related to the development or use of printed educational material, such as booklets, aiming at prevention of HIV-VT was found.

Thus, this study is relevant because it is the first one to develop an educational booklet, which intends to guide, standardize, systematize and stimulate health education actions as an approach to the prevention of HIV-VT. Therefore, the objective of this study was to describe the process of development and validation of a booklet for HIV-VT prevention.

Methods

This was methodological research developed using the following steps: 1. bibliographic survey; 2. development of educational material; and, 3. validation of those materials by experts in the subject and representatives of the target audience.⁽⁷⁾

In stage 1, a situational diagnosis was performed by means of an informal interview with five HIV positive pregnant women, attending the high-risk prenatal care at a referral hospital in Fortaleza-CE, Brazil, in order to investigate their main doubts about the care necessary for prevention of HIV-VT, and to verify their knowledge deficits. Subsequently, guided by demand for information demonstrated by the women, the main publications of the MH for the care that mothers should have to prevent HIV-VT were compiled. The descriptors "vertical HIV transmission" and "HIV" were used for research. All the publications on the subject were submitted to reflective reading in order to extract as much relevant information as possible for the booklet.

In stage 2, the texts were written in a clear and succinct way, addressing the care for the prevention of VT during prenatal, childbirth and puerperium periods. Subsequently, an art specialist was consulted to draw pictures in an attractive and easy-to-understand way, based on the cultural context of the target audience. The programs used to create the illustrations were Corel Draw Essentials for drawing and Adobe Photoshop for coloring; finally, the layout of the booklet and configuration of the pages occurred within Adobe InDesign.

At this stage, the guidelines used were related to language, illustration and layout so that the health professional considered the preparation of printed educational materials to ensure they were readable, understandable, effective and culturally relevant, according to the standard of experts in the subject.

Stage 3 was the evaluation of educational materials. The booklet validation was obtained by means of experts' analysis, aiming for content and face validity, and face validity with the target audience.

At this stage, the researcher submitted the booklet to experts who were specialists in the studied concept. Nine experts were selected, as suggested by several authors,⁽⁸⁻¹²⁾ and the selection was conducted by means of network or snowball sampling.⁽¹³⁾ The experts identified by this type of sampling, and who met the pre-established criteria, adapted from the consulted publications,⁽¹⁴⁾ were invited to participate in the study.

The face validation by the target audience was performed by pregnant and HIV positive women, in two reference maternity hospitals in Fortaleza-CE. Thirty women were selected:⁽¹⁵⁾ 23 pregnant and seven postpartum women.

Inclusion criteria were pregnant and postpartum HIV positive women; pregnant women attending prenatal care; postpartum women in the rooming-in setting of the institutions during the period of data collection; women over 18 years of age. The exclusion criterion was the presence of a physical or mental health condition that could compromise understanding of the booklet. HIV positive pregnant women were selected by convenience methods, during the data collection period; postpartum women were randomly selected in the maternity hospitals of the study.

Two instruments were used for data collection: the first for experts, and the second for the target audience. Both were adapted from an instrument proposed in a previous article.⁽¹⁶⁾ The expert instrument was divided into two parts: the first had demographic data, and the second had instructions for completing the instrument and the evaluative items of the booklet. A total of 52 items were distributed in seven evaluative aspects; two regarding content validity (scientific accuracy and content) and the remaining five related to face validity (literary presentation, illustrations, sufficiently specific and understandable material, legibility and printing characteristics, and quality information).

The instrument aimed at the target audience was also divided into two parts: the first with sociodemographic and gynecological-obstetric data of the pregnant and postpartum women;

the second included instructions for completing the questionnaire, as well as the booklet of assessment items, totaling 41 items, distributed in the same five aspects of evaluations as was presented to the experts.

The Content Validity Index (CVI) was used for the booklet's content validity.⁽¹⁷⁾ Using a four-point Likert scale, based on the experts' answers regarding the degree of relevance, each item was classified as: (1) irrelevant, (2) of little relevance, (3) really relevant or (4) very relevant. To fit the data collection instrument of this study, the degree of relevance was equated to the degree of agreement among the experts: (1) totally disagree, (2) partially agree, (3) agree and (4) totally agree.

To evaluate the booklet, the calculation methods recommended by researchers in the area were used,⁽¹⁸⁾ in which the sum of all the separately calculated CVIs, is divided by the number of items of the instrument. As the booklet was validated by nine experts, the literature recommended a CVI cutoff point of 0.78.⁽⁹⁾ Regarding the face validity performed by both the experts and the target audience, the items that obtained a level of agreement of at least 75% positive responses were considered validated.⁽¹¹⁾

The study was approved by the Research Ethics Committees of the institutions where the research was conducted, and according to the recommendations of Resolution No. 466/12, receiving favorable opinions (no. 336,923 and no. 375.301).

Results

The results are presented in two distinct steps: development of the booklet and the booklet validation.

Booklet development

The first step of booklet development consisted of the content survey. A search was made in the MH publications that addressed the care that mothers should receive to prevent HIV-VT; 15 existing publications were found.

The booklet contents were organized in nine domains with the following subheadings: Presentation; What is HIV?; How do you know that you are HIV positive?; How is HIV transmitted from mother to child?; Introductory care page; Prenatal care for prevention of vertical HIV transmission; Childbirth care to prevent mother-to-child transmission of HIV; Post-natal care for prevention of vertical HIV transmission; Conclusion.

In the second step, the text was developed, followed by the drawing of illustrations, and the work was finalized with the layout. We sought to combine content rich in information, but objective, as very extensive materials can be difficult to read, and require language accessible to all social strata and levels of education.

The booklet was developed in A5 paper size (148x210 mm - 5.8 x 8.3 in) consisting of 20 pages in its pre-validation version. After diagramming, the researcher sent this version of the booklet for printing and then to the experts, to determine face and content validity. The final version of the booklet was entitled “How do you prevent mother-to-child transmission of HIV? Learn this here!”. Figure 1 shows the cover, layout and characters of the booklet.

Booklet validation

At this stage, the booklet was evaluated by experts and by the target audience. Initially, nine experts were selected: six female nurses, and three male physicians. The age of the experts ranged from 29-55 years ($M=41$, $SD=\pm 7.6$ years). Among the nine experts selected, two (22.2%) had a postdoctoral degree in the area, four (44.4%) had a doctorate in the subject, one (11.1%) had a doctorate in the area related to instrument validation, one (11.1%) had master's degree, and one (11.1%) held a bachelor's degree with additional specialization in this area.

In order to obtain content validity of the booklet, the aspects related to “1. Scientific Accuracy” and “2. Content”, were validated using CVI calculation. The face validity of the booklet was validated according the agreement level between the experts.

“Scientific Accuracy” obtained a CVI of 0.78; “Content” obtained a CVI of 0.96, indicating an excellent level of agreement among the experts for this aspect. The overall CVI of the booklet was 0.87, and was considered validated for content.

Although the overall CVI proved to be good (0.87), the evaluative aspect of the booklet, the “Scientific Accuracy”, obtained a borderline CVI (0.78). Among the evaluated items in this aspect



Figure 1. Representative illustration of the cover, layout and characters from the booklet “How do you prevent mother-to-child transmission of HIV? Learn this here!”

(if the content agreed with current knowledge, whether the guidelines presented were needed and correctly addressed, and if the technical terms were properly defined) two of the nine experts partially agreed to the items. Their suggestions were analyzed according to the relevant literature, and corrections were made.

To obtain face validity of the booklet, the level of agreement of the experts was calculated for the five evaluation aspects of the instrument. According to figure 2 (A), the level of agreement among the experts was high, varying from 91.1% to 100%, higher than the established minimum of 75%, which show face validity for the booklet.

According the high levels of agreement and the strong global CVI, it is noticed that the experts selected, in the great majority of the 52 evaluation items of the instrument, the options of either 3 (agree) or 4 (totally agree). However, some experts, despite having a good evaluation of the items, made suggestions for improvement of the booklet, both in its appearance and content, such as: changing the booklet title; replacement or exclusion of technical terms; reformulation of illustrations; simplification and restating of phrases, among others. These proposals were analyzed and accepted (Chart 1). At the end of the appearance and content validation by the experts, the designer was contacted and the

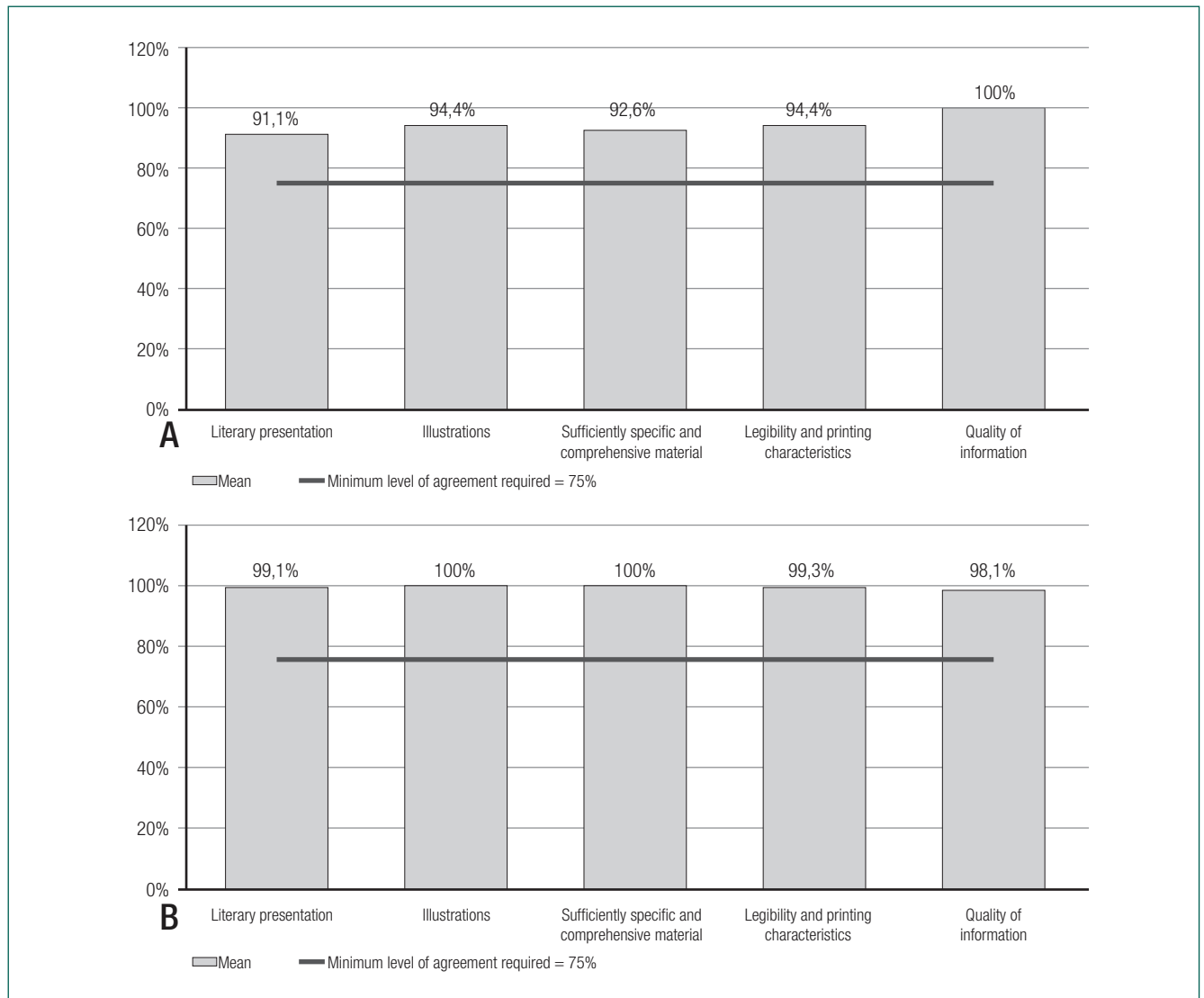


Figure 2(A). Level of agreement among experts for evaluative aspects of face validity. **(B).** Level of agreement between representatives of the target audience for evaluative aspects of face validity.

Chart 1. Some modifications made in the booklet from the suggestions of the experts and the opinion of pregnant and HIV positive postpartum women about the booklet

Judges suggestions	Modifications implemented
Title change	Replaced the title for "How do you prevent mother-to-child transmission of HIV? Learn this here!"
Replacement/exclusion of technical terms	Replaced "women infected with HIV" with "women with HIV"; Replaced "fertile age" by "reproductive age"; Replaced "transmission" with "transference"; The terms "standard test" and "rapid test" were replaced by "blood test from the vein" and "with a drop of blood from the finger", respectively; Replacement of the term "milk formula" with "powdered milk"; Excluded term "periodic" from "periodic examinations".
Illustration reformulation	Reformulated the figure of HIV, writing the name "HIV" inside the virus figure to facilitate understanding; Reformulated the condom figure; Reformulated the figure of the childbirth types; Removed the figure of the woman breastfeeding and a red "X", indicating that this practice cannot be performed, and replaced it with a figure of the mother with bandaged breasts, feeding the baby with artificial milk in a cup, with hearts around the mother/baby, demonstrating the love between them.
Simplification of phrases	Modified phrases for: "HIV is the virus that causes AIDS, a disease that attacks the body's defense system" and "With the right treatment, people with HIV can live for years without developing AIDS"; Retracted part of the sentence "... depending on the amount of HIV in maternal blood and the obstetric indication, according to the obstetrician and infectious disease specialist's assessment." The sentence was as follows: "The delivery may be vaginal or cesarean depending on the amount of HIV in the mother's blood and the medical indication".
Replacement of expressions	Replaced the "should not be" by "not recommended" in the sentence: "Breastfeeding is not recommended for mothers with HIV. " The word "decrease" was replaced by "prevent" in the sentence: "Bandaging the breasts or taking recommended medication may be advisable to prevent milk supply".
Units	Pregnant and postpartum women's opinions
Knowledge promotion	"I liked everything in the booklet; it promotes a high level of knowledge" (pregnant woman 1).
Booklet content	"The booklet is very attractive and has information we need to know" (postpartum woman 7).
Clarity	"The booklet is clear, explanatory, great. Only those who have difficulty with interpretation would not understand, because it is very simple" (pregnant woman 2);
Design and booklet illustrations	"The size is good, small and unobtrusive. I liked everything, I think that nothing needs to be added" (pregnant woman 2); "I really liked the figures" (postpartum woman 3).
Psychosocial aspect	"I liked it very much, because it shows the woman with HIV smiling, showing that we can be happy with our child" (pregnant woman 14).
Self-care and child care	"It made me understand a little more about this disease and how to better care for my child, to not become sick" (pregnant woman 19); "It contains important information to take good care of myself" (postpartum woman 2).

suggestions were implemented. The post-validation version was 28 pages long.

Regarding the face validation by the representatives of the target public, the majority (66.7%) of subjects were between 21-30 years ($M= 8.97$; $SD=\pm 4.93$). The level of education assessment showed that half of the participants had 0-8 years of school. The women answered the 41 items of the evaluation instrument of the educational instrument distributed in the five aspects regarding face validity, indicating "yes", "no" or "in part". This evaluation showed a level of minimum agreement on the positive responses of women for each of the five evaluative aspects (Figure 2(B)).

As shown in figure 2(B), all five evaluative face validity aspects achieved a level of agreement higher than the minimum established to be considered validated (75%), indicating an excellent level of agreement among pregnant and postpartum women with HIV. The booklet was considered to have achieved face validity for the target audience.

Among the 41 items evaluated by the 30 women, only three (0.24%) responses were marked "No", and seven (0.57%) "In part", ratifying the level of acceptance and responses during the assessment of the educational material. The women were asked to express their opinions about the booklet in general, at the end of the evaluation. Chart 1 shows a summary of this result.

Discussion

In the process of content and face validation of the booklet, the contributions of experts and representatives of the target audience were included. Although the overall CVI was satisfactory (0.87), the experts made suggestions for changes relevant to improving the booklet. In addition, most of the experts agreed with the applicability of the educational material to the clinical practice of the nurse. Other studies that validated printed educational materials also used the CVI to measure content val-

idation, and had to undergo adjustments until the validated final version was reached, demonstrating the importance of performing this step for development of quality educational materials.^(11,19)

This process of adapting educational materials to the experts' suggestions is an essential step to make the product more complete, more scientifically rigorous and effective for use during the health education activity. This stage is also referred to by other studies as having great relevance for the improvement of the material to be validated, in which, likewise, the reformulation and the exclusion of information, substitution of terms, as well as the reformulation of the illustrations were suggested.^(19,20)

The development of quality educational materials enables educational interventions based on structured knowledge and information that is appropriate for the clientele. In the context of HIV-VT, such interventions are necessary to develop positive behaviors and increase adherence to prophylaxis, in addition to the need for greater professional involvement with health education and the clientele.

The establishment of human relationships is essential in the HIV-VT, as supporting a seropositive woman does not only involve a set of techniques. The nurse needs to understand the practices related to the reduction of HIV-VT in a comprehensive way.⁽²¹⁾ The ethical, social and cultural dimensions that regulate the lives of HIV positive women should be available for dialogue, and linked to gender, sexuality and reproductive health issues. Thus, the women's decisions and desires should be discussed in during care, aiming to provide women with adequate information on the safest recommendations for family planning, care needed during pregnancy, childbirth and the puerperium, as well as respect for their rights as citizens.⁽²²⁾

The multidisciplinary nature of the experts who evaluated the booklet is important. The evaluation by professionals from different areas is the occasion when it can really be said that the work is being conducted in a team, valuing the opinions and different approaches on the same theme. The development of educational materials is also an opportunity to standardize and formalize behaviors related to patient care, with the participation of all.^(7,20)

The target population also evaluated the booklet in a positive way, considering it important for the promotion of knowledge, with rich content combined with clarity, adequate format and explanatory illustrations. In addition, the relevance of the booklet was mentioned to support some psychosocial aspects, such as happiness and quality of life improvement, and promoting self-care and childcare.

The experts' suggestions regarding clarifying the importance of certain care were essential to strengthen the autonomy of women, by means of acquisition of a better-informed knowledge. We desire to properly guide mothers living with HIV/AIDS, and enable them to be caregivers of their children who have been exposed to HIV. This guideline, however, should allow these women to become protagonists of their own existence, with greater autonomy to provide safe care to their children, as well as themselves, achieving a better quality of life.⁽²³⁾

The statements expressed by women show the stigma permeating the condition of being HIV positive. The need for psychological support and more attention during educational activities is also evident, as psychosocial factors are strongly present in relation to the acceptance of the infection, which interferes in self-care and childcare.

The HIV positive woman, known to be a carrier of a lethal disease, lives with distressing feelings, such as fear, shame, anxiety and depression. Associated with all these feelings, they experience stigma, prejudice, isolation, and abandonment, experiences inherent to revolt and indignation, suffering, as well as the fear of death. The importance of family support is emphasized as an important factor in living with the disease.⁽²⁴⁾

Validating the educational material with representatives of the target audience is a necessary attitude and an important gain for the researcher and the team involved. It is the moment in which there is a realization about what is lacking, what has not been understood, and the distance between what is written, what is understood and how it is understood.⁽⁷⁾

The limitation of this study was the lack of validation by a specialist in the communication field. Having completed the development and validation

of the booklet, the study does not end here, but the booklet will undergo continuous updates based on scientific progress, and it is intended to use validated material in the specialized services, as well as to conduct future research to assess its effectiveness in achieving the implementation of measures to reduce HIV-VT. Finally, the support of government agencies is necessary for reproduction, dissemination and wide distribution of this material in the health services, in different media, in addition to the printed version.^(25,26)

Conclusion

The objective of the study was to describe the development and validation of an educational booklet for prevention of HIV-VT, which is the first to be developed on the subject. The booklet was validated according to face and content validity by experts, and achieved face validity from representatives of the target audience, and should therefore be considered in the context of educational activities to be an instrument capable of favoring preventive measures for the HIV-VT. The use of this material with HIV positive women, from the preconception through the postpartum periods, will facilitate the practice of evidence-based nursing. It is an illustrated tool capable of encouraging dialogue between professionals and women, to facilitate their acquisition of knowledge, to retain information on necessary care for the prevention of HIV-VT, empowering them, as well as providing a means to standardize the guidelines given by professionals.

Collaborations

Costa Lima ACMAC contributed to the study design, research, article writing, relevant critical review of the intellectual content, and final approval of the version to be published. Bezerra KC and Souza DMN contributed to the study design, article writing, relevant critical review of the intellectual content, and final approval of the version to be published. Rocha JF contributed to the study design, article writing, and final approval of the version to be published. Oriá MOB contributed to the analysis, data inter-

pretation, review of the intellectual content, and final approval of the version to be published.

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