

Short film on HIV disclosure to children: assessing a health literacy strategy

Curta-metragem sobre revelação do HIV à criança: avaliação de uma estratégia de letramento em saúde

Cortometraje sobre revelación del VIH a niños: evaluación de una estrategia de alfabetización en salud

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ABSTRACT

Objective: to evaluate the potential of the short film *Nossas Histórias* [Our Stories] about preparing family members of children with HIV in the disclosure process, as a health literacy strategy. **Method:** this mixed-method study of twenty-eight nurses from three regions of Brazil was conducted in 2018 using a Likert-type scale and the wheel method. Statistical analysis (with content validity index greater than 0.80) and thematic analysis were performed. **Results:** Analysis returned CVI = 0.89 in the title; CVI = 0.84 in the waiting room, CVI = 0.94 in the nursing appointment; and averages of 0.94 characters and 0.89 nursing consultation in the development of the story. Positive points of the short film were its diversity, time and pleasant aesthetics. **Conclusion:** the short film's content was found to be a strategic innovation with potential for health literacy and application in nursing consultations in advocacy care for children with HIV.

Descriptors: Pediatric Nursing; HIV; Family; Health Literacy; Disclosure.

RESUMO

Objetivo: avaliar o potencial do curta-metragem “Nossas Histórias”, sobre o preparo dos familiares da criança com HIV no processo de revelação, como estratégia de letramento em saúde. **Método:** estudo com método misto, implementado com a escala do tipo Likert e o método da roda. Participaram 28 enfermeiros de três regiões do Brasil em 2018. Foram realizadas análise estatística com índice de validade de conteúdo (IVC) superior a 0,80 e análise temática. **Resultados:** após análise, obteve-se IVC=0,89 no título; IVC=0,84 na sala de espera, IVC=0,94 na consulta de enfermagem; e média de 0,94 personagens e 0,89 consulta de enfermagem no desenvolvimento da história. Pontos positivos do curta-metragem foram: diversidade, o tempo e a estética agradável. **Conclusão:** avaliou-se que o conteúdo do curta-metragem é uma inovação estratégica com potencial de letramento em saúde e de aplicação em consultas de enfermagem no cuidado de advocacia da criança com HIV.

Descritores: Enfermagem Pediátrica; HIV; Família; Letramento em Saúde; Revelação.

RESUMEN

Objetivo: evaluar el potencial del cortometraje “Nossas Histórias”, sobre la preparación de familiares de niños con VIH en el proceso de revelación, como estrategia de alfabetización en salud. **Método:** Estudio de método mixto, implementado con una escala tipo Likert y el método de la rueda. Participaron 28 enfermeros de tres regiones de Brasil en 2018. Se realizaron análisis estadísticos con índice de validez de contenido (IVC) superior a 0,80 y análisis temático. **Resultados:** Después del análisis, se obtuvo IVC=0,89 en el título; IVC=0,84 en la sala de espera, IVC=0,94 en la consulta de enfermería; y promedio de 0,94 personajes y 0,89 consulta de enfermería en el desarrollo del cuento. Los puntos positivos del cortometraje fueron: diversidad, tiempo y estética agradable. **Conclusión:** se evaluó que el contenido del cortometraje es una innovación estratégica con potencial para la alfabetización en salud y aplicación en consultas de enfermería en la defensa de los derechos del niño con VIH.

Descriptores: Enfermería Pediátrica; VIH; Familia; Alfabetización en Salud; Revelación.

INTRODUCTION

Health literacy means incorporating functional, interactive, and resolute activities to comprehend health issues and apply them to decision-making in several clinical contexts where nurses act as health information mediators for family members of children with HIV^{1,2}.

Acquiring abilities of health literacy is a process that extends itself throughout life. As, gradually, the child and his/her family gather new ways of caring when they face new personal health requirements³. It involves decision-making abilities to navigate the health system. Health literacy may be considered a social determinant that articulates two different fields, health, and education, to develop the capacity to care for oneself and promote the empowerment of individuals from childhood^{4,5}.

Furthermore, health literacy resonates with nursing advocacy, which consists in increasing the knowledge of a child's rights to have access of information through his/her family member. Studies show that revealing HIV during childhood favors ART adherence and collaborates to a better quality of life⁶⁻⁷. Thus, family members and health professionals should recognize their right to access quality information in a protected environment, getting well

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informed to prepare themselves for the disclosure process, which includes pre-disclosure, disclosure itself, and post-disclosure. Pre-disclosure includes preparing the child to receive information about HIV, giving him/her information according to their age, what a virus is, CD4 title, how the immune system works, and other relevant information about living with a chronic health condition. Disclosure itself involves more than naming HIV; it includes the meaning of being diagnosed with a stigmatized illness and, in the long run, how it has affected him/her lifestyle so far. Post-disclosure is regarded as questions about the illness and the future of HIV, deconstructing ideas of stigma and prejudice around it^{6,7}.

Health literacy was essential for family members in Sub-Saharan Africa to own knowledge and converse better with children when they disclose that they were living with HIV and the need to care for themselves⁸. In Peru, rap music videos were used among the health literacy strategies to conduct the conversation about HIV with children. Such initiatives represent a plurality of experiences that trigger the need for knowledge exchange in favor of personal health. With global expansion for digital inclusion, a fertile environment to develop and access health literacy technology within the context of HIV disclosure to the child was created. Alongside what happens around the world, in Brazil, nurses' participation in preparing family members is also imperative for ethical advocacy care in favor of the child's best interest. However, Brazilian nurses highlight a lack of dynamic interactive resources in daily practice for nursing consultation. Such tools can assist in conversing with family members on preparing for HIV disclosure to the child⁹.

The use of video is another possible resource to mediate information about the HIV disclosure process because it combines different languages (visual and audio) in a clinical setting in a nursing consultation. "Our Stories" short film is an in-movement technology to meet clinical care needs. Its production consisted of extracting narratives from a master's research data base¹⁰ that composed stories of seroconcordant and serodiscordant people. Characters in the script were inspired by family members staged in dramas of three family groups in an outpatient follow-up consultation in a seven minute and twenty-six second production¹¹. The nurse's character was the interlocutor of scientific knowledge represented by the themes emerging from the analysis of narratives when talking about a) counseling in the disclosure of HIV in childhood, b) communication to the child about the sensitive HIV topic, c) clues to the child's readiness to be informed about HIV, and d) stigma and prejudice in disclosure.

This study aimed to evaluate the potential of the short film "Our Stories", about preparing family members of children living with HIV in the disclosure process, as a health literacy strategy.

METHOD

An evaluation study of a short video was implemented with a mixed research approach. This type of research adopts quantitative and qualitative procedures, appropriating the objective and subjective dimensions to answer a research question, in a complementary way. Sequential explanatory strategy was applied, in which the qualitative data provided an in-depth interpretation of the quantitative data¹². The interpretive lens in this study was the knowledge-to-action model of the knowledge translation strategy¹³.

Quantitative component corresponds to objective evaluation of the short-film script by specialists, with the application of a questionnaire with the Likert type Scale, in which clear, concise, and direct propositions express hypothetical and desirable behaviors¹⁴. Scale was adapted and answered in the Google Docs[®] platform, with a personalized visual identity¹⁵. First section of the electronic instrument consisted of an introduction to the research aims. Second section consisted of the script presentation and instructions for filling out the scale. In the third section, the scale with 23 propositions and their assertions. Each proposition included five measurement levels - inadequate (1), little inadequate (2), little adequate (3), Adequate (4), and very adequate (5). A space was set aside for recording additional observations to the assertion.

In each of the four blocks, adequacy or not of the script was verified, considering the following variables: title, setting (office consultation and waiting room environment), characters through the dramas' relevance of each family group, and health literacy strategy, scientific content.

Recruitment for the quantitative step occurred with four strategies were adopted: 1) search by topic with keywords ('child health', 'pediatric nursing' and 'HIV/AIDS') on the Curriculum platform of Brazilian researchers; 2) identification of national pediatric nursing authors; 3) nurses who participated in a child health research group at the Federal University of Rio de Janeiro and 4) in social networks.

For the statistical treatment, relative and absolute frequencies were adopted, and the calculation of the global Content Validity Index (CVI) with values equal to or greater than 0.8019-21 to assess the agreement between experts for the set of propositions, applying the following formula: $CVI = \frac{\text{Number of responses "4" and "5"}}{\text{Total number of responses from participants}}$

Global CVI consists of the sum of the CVI of each assertion, divided by the number of assertions. The calculation of CVI was made by adding the positive items ("4" and "5") divided by the total number of responses. Items "1", "2," and "3" indicate the need for revision or exclusion to improve the script and solve possible communication problems in the health literacy of that scientific information.

Qualitative component was employed through the conversation-wheel strategy¹⁶ because it provides collective meeting spaces and group dialogues for participants who value their knowledge in creating collective strategies for change through decision-making, mediated by simultaneous and continuous dialogue for the collection and analysis, reflection, circulation of information, and exchange of ideas.

Participants were recruited from a research group at a public university in the city of Rio de Janeiro. The selection criteria were having a degree in nursing, working in pediatrics for a minimum period of three months and participating in scientific research in the area. Of the 15 invited participants, 12 confirmed the appointment by telephone.

In the months of July and August 2018, 67 people made their contact information available with an interest in participating in the research. For this group, the instrument adapted from Fehring criteria¹⁷ was applied for expert recognition (minimum score 5), resulting in 19 participants. This sampling is consistent with the number of other studies that applied the Likert scale to assess educational technologies^{18,19}.

Three meetings were held with four nurses for three weeks, with 12 participants. Each meeting lasted an average of 30 minutes, recorded and fully transcribed. After the short film screening, the participants debated, based on a triggering question (How do you rate the short film concerning the choice of...?).

For the qualitative data, an empirical material of 18 pages was added to Portuguese linguistic materiality. Then, the events were chronologically ordered, and repetitions of colloquial language were suppressed, resulting in seven pages of the textual corpus. In preparing the text for analysis, we tried to keep it free from the judgment of values and personal opinions. Textual corpus was submitted to the thematic analysis procedure²⁰ in three stages - pre-analysis, material exploration, treatment of results, and interpretation total number of responses from participants.

Criteria for closing qualitative fieldwork are not static and depend on the context, research objective, and data quality, with the number of participants varying according to the depth of the material²¹. Geographic representativeness and diversity of clinical practice were ensured in caring for the population of children with HIV and their families in Rio de Janeiro. In the conversation wheel's turning, no new contributions emerged from the second meeting.

Institutional Review Board approved the research project. All participants (n=28) had to sign the Informed Consent before initiating the research fieldwork, clearly stating their right to confidentiality and data protection.

RESULTS

Of 31 participants, three participated in both components. Thus, in both components, there were a total of 28 respondent people in this research, which were represented by 27 female and one male. Three regions South (7), Southeast (20) and Northeast (1) were represented. Their level of education consisted in bachelor's degree (2), Specialists (9), Masters' Degree (6) and Doctor's Degree (10). Only one nurse had no clinical experience.

Nine scenes of the script (dramas and transition) translated scientific content on the communication of the child's diagnosis, orphanhood, and foster care (scene 4); late discovery of diagnosis, discovering of HIV in the family, and sibling serodiscordance (scene 6); readiness cues at school age as conducive to HIV disclosure, the right of access to information, counseling and choice of environment for disclosure (scenes 7 and 8). Finally, adequacy of language by the nurse to talk to the family member about the disclosure (scene 9). Adequacy of the short film title, the short-film story, scenario, and adaptation of the short film history's character is presented in Table 1.

TABLE 1: The short-film “Our Stories” (named in Portuguese “Nossas Histórias”) was evaluated by specialists according to the title, setting, characters, health literacy strategy, and scientific content. Rio de Janeiro. 2018

Blocks	Specialist nurses (N=19)		
	n	%	CVI
Title	17	89.48%	0.89
Setting			
Nursing consultation room	18	94.73%	0.94
Waiting Room	16	84.21%	0.84
Characters			
Nurse Priscila	19	100%	1
Aunt Isabel (extended single parent family)	18	94.73%	0.94
Clarissa and Luana (mixed female homosexual family)	18	94.73%	0.94
Joana and Carlos (mixed heteroaffectedive family)	19	100%	1
Health Literacy Strategy			
Nursing Consultation as a strategy adopted for the development of the characters' stories	17	89.48%	0.89
Scientific Content			
Communication of the child's diagnosis	16	84.21%	0.84
Orphanage	16	84.21%	0.84
Welcoming	18	94.73%	0.94
Late diagnose discovery	18	94.73%	0.94
Discovering HIV in the family	18	94.73%	0.94
Serodiscordance between siblings	15	78.95%	0.78
Child readiness cues to receive HIV information	17	89.48%	0.89
School age as the ideal time to reveal the child's HIV to her	15	78.95%	0.78
Counseling for disclosure	18	94.73%	0.94
Child's right of access to information	18	94.73%	0.94
Environment for disclosure	18	94.73%	0.94
Language adopted by the nurse to talk to the family member about the disclosure of HIV	17	89.48%	0.89

Although half of the experts considered the neutral environment as applicable to the waiting and consultation rooms of a hospital outpatient clinic or a primary healthcare unit, only two respondents associated them as positive. Recovering latent memory, professional experiences of six nurses in primary and hospital outpatient care indicated the lack of decorative elements that represented those rooms as a care environment.

I liked the consultation room because it's clean, there is no information and no other furniture. (E1a e E9c)

I found the waiting room empty. The white background and the black chairs. The waiting room has people passing by and people sitting, circulating, (...) I was thinking about the hospital outpatient clinic. I found the consulting room table empty. The waiting room (...) has a lot of information... (E5b, E6b, E7b, E10c, E11c e E12c)

They highlighted improvements in the scenario where the dramas were staged and in the identification of the nursing consultation room to recognize and give visibility to the nurse's role in preparing family members to reveal HIV to HIV-positive children.

...a sign on the room door that the nurse attends, written nursing consultation to indicate that a nurse works there. (E2a)

As for the character variable, the nurse was a 27-year-old black woman born in southeastern region who graduated from a federal university five years ago. Costumes' composition was concerned with meeting the specificity of the children's clientele, including wearing a colorful coat, using children's accessories, and identifying with an institutional badge. Her hair is tied back, and she wears a small, colorful earring. This character's composition has achieved CVI equal to one.

Qualitatively, visual language and dramas were evaluated in the scenes that contextualize qualified listening as scientific content translated into the narrative of the nurse character.

...get the message across. It's well done. The information is not played. We can identify the focus [in] the professional [by] being available, attentive, and having a qualified listening.

How the Nurse's character communicated with the families conveyed security, contributing to the gradual, unhurried, respectful, and encouraging process of preparing for the disclosure. I liked the Nurse's character; she

shows confidence, speaks slowly, and is always willing to listen to people to look them in the eye. (E1a, E2a, E3a, E5b, E8b, E10c)

However, the single and exclusive use of the verbal narrative in the dialogue between the Nurse's character and the family member was evaluated as simple. They suggested the inclusion of toys and drawings as mediating resources for interaction. Furthermore, this recommendation applies to situations where the Nurse participates in the disclosure to the child at the family's request.

She always talks about using the simplest language, but it does not exemplify how it could be approached. For example, toys, and drawings. (...) (E1a, E2a, E3a)

An extended single-parent family (CVI = 0.94), represented by the character Aunt Isabel, had a white phenotype. This character guided the orphanhood drama since she was responsible for the care of the child whose parents died of AIDS. In addition, biographical background of a family depends on the benefit of the continued benefit granted to the child by the Single Social Assistance System (SUAS) in Brazil. Drama highlighted an example of unstructured disclosure, mediated by a language of fear, leading to the nurse's use of health literacy as an intervention strategy. It suggested adopting simple, accessible, and appropriate language for the child's understanding in the therapeutic and preparation dialogue

Characters Clarissa and Luana were representatives of the mixed female homosexual family (CVI = 0.94). Clarissa, a 32-year-old woman, living with AIDS, lives in the west of Rio de Janeiro city; she was married to a man with whom she had a son, Manoel. Discovering HIV in the child led to the investigation of both parents, who were later diagnosed. Two months later, the couple broke up, which led her to blame her father for the infection. Manoel's father died a year after his diagnosis was discovered. Currently, Clarissa lives in an affective relationship with Luana, a 31-year-old serodiscordant black woman who helps her care for Manoel.

In the conversation circle, gender, sexual orientation, and racial diversity were evaluated as positive in the short film, adding value to the health literacy tool as it promotes inclusion.

They were great; the representation of the same-sex couple, a black woman. (E5b, E6b e E8b)

Finally, the mixed heteroffective family (CVI=1) is represented by the serodiscordant characters Joana, who lives with HIV, and Carlos. Both are responsible for the care of Caio, a twelve-year-old child who lives with HIV and asks his parents why his treatment routine involves the continuous use of medication and regular visits to the health service.

Adequacy of the nursing consultation to the health literacy strategy

In the written script, health literacy strategy of the Nursing consultation was evaluated as adequate (CVI=0.89) for developing the stories of single-parent, mixed female homoffective and heteroffective families to translate scientific information.

Characters of the nurse and family members presented a self-explanatory audiovisual language capable of arousing the audience's interest. Combining dramas with the moving image allowed the intersection of the stories with cohesion. Additionally, it occurs within a time suitable for the preparatory approach to disclosure, as part of a nursing consultation, without tiring the spectator.

The video is for the nurse, but it is useful for the family member. I liked it. It was interesting. I didn't notice any problems with the script. Accessible language is explanatory, with good vocabulary. Timeframe is great. (...) (E1a, E2a, E3a, E4a, E5b, E7b, E8b, E9c, E10c, E11c e E12c)

Vary situations enacted explored different facets of the phenomenon of preparing family members for HIV disclosure, initiation, conflict, and resolution well demarcated by the passage of time. Keeping the viewer attentive to the outcomes of the dramas of each family group was positively evaluated.

The video has diversity and excellent composition. Initial situation is triggering, (...) Two situations have unraveled. This "Five years later..." is interesting because it holds [the viewer's attention]. (E6, E8, E9c, E10c e E11c)

Scientific content addressed in each scene was translated with pertinence and property in the script. Orphanhood, the discovery of the diagnosis, the family discovery of HIV, and readiness clues are exemplified as dramas in the biographies. However, they emerge in the scenes as a form of scientific information in the nurse's speeches to promote health literacy during the consultation.

The message of hope in the outcome of the dramas, mediated by the nurse's character in the therapeutic encounter with the family groups, was evaluated as positive. Translated scientific content indicates a shift from the conception of living with HIV, as a fatal condition, to a chronic condition, with possibilities for the future.

(...) cool to finish with the part of 'building a family' [positive reinforcement about living with HIV]. Today, there is treatment, [and the person with HIV] has a normal life. (E3a, E6b, E9c e E11c).

DISCUSSION

Audiovisual tools consist of resources that simultaneously stimulate the senses of hearing and vision, the most common being video. It combines the languages of image, movement, and sound, forming an expression system capable of articulating a network of signs that guide the communicative process, sometimes for perception, sometimes for cognition²². Among the complex and sensitive themes that can be approached with health literacy²³, disclosing HIV to children living with this condition represents a challenge for family members and health professionals.

The video as a tool for disseminating information is powerful for nurses in health spaces. Displaying a video on hemodialysis to people undergoing this treatment showed an improvement in phosphorus levels three months after the intervention. Patients learned about managing their health condition and incorporated this knowledge and practices into their day-to-day self-care, reflecting on clinical examinations in the future²⁴.

The video is an educational technology that the nurse can use during care to address a topic, illustrate situations and interventions, stimulate discussion on a subject, build confidence and tranquility about the future and promote adherence to treatments that result in improved health and quality of life^{25,26}.

Visual language and dramas of a short film are little explored as educational technology, in which dramas move the scenes, constituting stories with beginning, conflict, and resolution. The spectator can transport himself to the scene, creating an identity that leads them to construct their reality interpretations. Its integration into the health reporting process promotes reflection and makes learning more motivating, revitalizing forgotten knowledge and improving health literacy²⁶⁻²⁸.

Nurses positively evaluated the short film in the technical aspects that involved the time and length of the stories, temporal markers of the passage of time, the demarcation of the target audience, adequacy of the script, and dialogue with the scientific content.

One methodological study produced and evaluated a video on intestinal rehabilitation in individuals with spinal cord injury showed a high agreement rate (94%) among the experts on the items that referred to the content addressed²⁹. Both quantitative and qualitative indicators can suggest a better characterization of characters in dramatic scenes, inspired by biographies and real stories shared with the nurse in clinical consultations, using language of a short film as a tool for disseminating health information.

Inner aspect is represented by everything that occurs in the character's life, from his birth to the film's scene, which includes biography, feelings, costumes, and all the backstory that adds complexity to his constitution. External aspect, on the other hand, involves the way the character positions himself, acts, and his role in the story represented in the film, that is, his speeches, his gestures, and everything that is seen in the scene³⁰.

Inner aspects of the single-parent family, AIDS emerges as a disabling condition that qualifies the socially vulnerable child to receive a monthly income of a national minimum wage as a benefit of continued provision, by the government social insurance, for guaranteeing essential supplies of survival. In Brazil, guaranteeing the child's fundamental rights (housing, health, school, food) with absolute priority is the duty of the family, society, and the state. Children living with AIDS are in a situation of vulnerability due to their condition in society that depends on the consent of an adult to make decisions about their own lives and because they have a chronic health condition³¹⁻³³.

External issues include the visual language of the nurse character. Wearing a colorful outfit suggests that this kind of clothing decreases the child's anxiety and eases interaction between him/her and the health professional^{34,35}.

Language and how the character presents clear guidelines on how to reveal the seropositivity of the child living with HIV, involving revealing it (gradual, on different days), respecting the child's age and stage of development, was considered adequate.

Using simplified and colloquial language, considering how the child expresses himself and not how the adult expects him to express himself during HIV disclosure, is beneficial for the child³⁶. Playful language in which a hero (antiretroviral) and thug (HIV) story is constructed is currently discouraged by researchers^{36,37}.

Thus, we decided not to modify the video narrative, because we understand the nurses might not have been in contact with these findings; and the short film can be the place for them to do so.

CONCLUSION

Short-film evaluation consisted in identifying the internal content validation of the screenplay (quantitative component) and the video (qualitative component).

Internal content validation reached, respectively a CVI of 0.89 in the title; 0.84 in waiting room, 0.94 in nursing consultation; and an average of 0.94 in characters and 0.89 nursing consultation in the story development. Regarding the 12 themes addressed in the scenes, ten were validated. "*Our Stories*" is an innovative resource with potential for clinical application of advocacy care by nurses in nursing consultations. Positive points include diversity of families, ethnicity and race, the time, and pleasant aesthetics stand out. Adjustments to the scenario, staging, and framing are necessary so that it converses with nurses' reality.

Technological innovation in the form of a motion picture demands methodological procedures to make it culturally sensitive and accessible to the target audience. Among others, potentialities include the possibility of expressing interaction nuances in the relationship established by the nurse and the family member who cares for the child because motion picture allows translating emotions and interactions, and sounds add dynamism to the scenes which favor the apprehension of information. The content of the short film was considered strategic innovation with the potential for health literacy and application in nursing consultations in advocacy care.

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