

A STORY FOR CHILDREN TO HELP CHILDREN WITH HIV UNDERSTAND THE HEALTH-DISEASE PROCESS

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ABSTRACT

This study analyzed how a story for children related to AIDS contributed to the understanding of the health-disease process of children with HIV. It was conducted at the Pediatric Clinic in Porto Alegre/RS from May to December 2011. The participants were five children aged between seven and nine years and their caregivers. The data were collected by a focal group through interviews and submitted to thematic content analysis. Two categories were found: identification with the story, relationship with the health-disease process, understanding of the story, and the health-disease process. The results demonstrated that stories for children are resources to talk about the health-disease process with children without revealing the diagnosis, leading them to understand their situation and the importance of treatment. We considered that this resource may be a strategy to help the caregivers and health professionals to initiate the process of revelation of diagnosis.

Descriptors: Nursing. Child. HIV. Juvenile literature.

RESUMO

O estudo analisou como uma história infantil, contendo questões relacionadas à Síndrome da Imunodeficiência Adquirida, contribui para a compreensão do processo saúde-doença pela criança com o Vírus da Imunodeficiência Humana. Foi realizado, em Porto Alegre, RS, entre maio e dezembro de 2011. Participaram cinco crianças, com idades entre sete e nove anos, e seus cuidadores. Utilizou-se grupo focal e entrevista, e os dados foram submetidos à análise temática de conteúdo. Emergiram duas categorias: Identificação com a história e a relação com o processo saúde-doença e Compreensão da história e do processo saúde-doença. Os resultados demonstraram que a história infantil é um recurso para conversar com as crianças sobre o processo saúde-doença sem revelar o diagnóstico, levando a uma compreensão de si e do tratamento. Considera-se que esse recurso pode ser uma estratégia para auxiliar os cuidadores e profissionais da saúde a iniciar o processo de revelação do diagnóstico.

Descritores: Enfermagem. Criança. HIV. Literatura infanto-juvenil.

Título: A história infantil como recurso na compreensão do processo saúde-doença pela criança com HIV.

RESUMEN

El estudio analizó cómo el cuento infantil con cuestiones sobre el SIDA contribuye a la comprensión del proceso salud-enfermedad por el niño con VIH. Fue realizado en clínica pediátrica de Porto Alegre/RS, de mayo a diciembre de 2011. Participaron cinco niños entre siete y nueve años y sus cuidadores. Los datos fueron recogidos en grupo focal y entrevista y analizados por medio del análisis temático de contenido. Emergieron dos categorías: La identificación con la historia y la relación con el proceso salud-enfermedad; y La comprensión de la historia y del proceso salud-enfermedad. Los resultados demostraron que el cuento infantil es un recurso para hablar con niños sobre el proceso salud-enfermedad, sin revelar el diagnóstico, llevándolos a una comprensión de su situación y la importancia del tratamiento. Consideramos que ese recurso puede ser una estrategia para ayudar a cuidadores y a profesionales de salud para iniciar el proceso de revelación.

Descriptores: Enfermería. Niño. VIH. Literatura infanto-juvenil.

Título: El cuento infantil como recurso en la comprensión del proceso salud-enfermedad por niños con HIV.

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INTRODUCTION

After 30 years of the first cases of Acquired Immunodeficiency Syndrome (AIDS) in Brazil, stigma and prejudice associated with this condition are still present. Children infected by vertical transmission grow up with Human Immunodeficiency Virus (HIV), attend school, have leisure activities, but many are unaware of their health status unless they have a chronic disease that requires follow-up throughout life.

According to the evolution of the epidemic, the stigma of “risk groups” characterizes these subjects according to a set of concepts (psychological, social, political, medical) that turn HIV-seropositive people into just a virus carrier who need to keep their disease a secret⁽¹⁾.

In children, the lack of knowledge about their diagnosis may generate consequences during treatment, such as non-adherence to medication or resistance to ambulatory treatment. Due to the difficulty in conversing with children, families adopt strategies of concealment and often require professional support to reveal or even to start the process⁽²⁾.

Accordingly, this study was conducted from the perspective of alternative care that can be used by families and professionals involved with children with AIDS, particularly nursing staff. Meetings with the child with the purpose of clarifying the disease process, weekly or fortnightly activities, interviews with family members, discussion of fantasies, anxieties and fears in addition to stimulating the children to express themselves in a spontaneous way about the disease are recommended actions⁽²⁾. With this in mind, a story was written for this audience with the objective of relating situations that are similar to those that the child experiences.

Therefore, this article focuses on the use of a story for children written to discuss the life of the characters – children with AIDS – to address the relationships between families and school, the strengths and weaknesses, joys and sufferings. The story “Peter’s and Julia’s Discovery: conversing about health and illness” is composed of five chapters and it was written to be an alternative way to discuss HIV in childhood.

Thus, it is believed that the practice of telling this story encourages conversations among children, seeks to minimize bias, and provides opportunities so that children in need of continuous

monitoring may have more quality of life and living quality. The construction of a literary text must encourage the pursuit of fundamental questions of human existence, which also affects children⁽³⁾.

In order not to disclose the AIDS diagnosis to the child, care has been taken in the textual construction such as forms of infection, denomination of the disease, and diagnosis of parents with the purpose of placing important elements for the processing of social information. Few studies have sought to understand the development of the disease using stories for children. It is a field that must be considered as a resource in child healthcare⁽⁴⁾.

Literature combines fiction and truth. The art of storytelling, sharing, creating and recreating social worlds also constructs cultural and historical knowledge. Thus, it admits an indirect educational role and it is considered a mediator for human learning⁽⁵⁾.

This article is the result of a research, which resulted in the dissertation “A story for children to help children with HIV understand the disease process”⁽⁶⁾, whose aim was to analyze how a story for children containing issues related to HIV/AIDS (continuous use of medication, secrecy, secret, side effects, tests, hospitalizations) contributes to the understanding of the disease/health process of children with HIV. In this article, we discuss how a story for children can help encourage conversations with the children about their treatment.

METHOD

This is a qualitative, descriptive and exploratory study. It was conducted at the Pediatric Outpatient Clinic of the Hospital Group Conceição, Porto Alegre, Rio Grande do Sul. Five children between the ages of seven and nine years living in Porto Alegre and the metropolitan area of Porto Alegre, who were on medication, unaware of the diagnosis named “HIV/AIDS”, were not homeless, had no cognitive problems, and had a caregiver responsible for them, participated in the study. The participation of the guardian was only to provide information about the child such as, address, education, family income, number of siblings, and other aspects, and to inform if the child was aware of her diagnosis or not.

Data collection began after the first contact with the objective of explaining the research and

signing the informed consent form (Res. 196/96, CNS). The five children participating in the study signed a consent term at the first group meeting when the research activities were explained to them. Three focal group meetings were held every fortnight with the same children and the interviews were recorded on audio.

The Project was approved by the Research Ethics Committee of the Hospital Group Conceição (No 10-199). The psychologist of the institution participated in the data collection to provide support to possible complications, such as accidental disclosure of diagnosis or onset of feelings that could bring discomfort to the children. One of the children was aware of her diagnosis without the consent of the family and she revealed it to the researcher at the end of the last meeting. The child and the caregiver were referred to the Department of Psychology.

The activity used to trigger the meetings was the storytelling of chapters of the story "Peter's and Julia's Discovery: conversing about health and disease" in order to respect the understanding of the issues involved in the disease-health process. The meetings were held in a prearranged location, known to the children and without interference by others.

To ensure anonymity, participants' names were replaced by the following codes: child 1 (C1), child 2 (C2)..., and groups 1 (G1), 2 (G2) and 3 (G3) and the researcher is identified as P.

The information obtained was transcribed and submitted to thematic content analysis⁽⁷⁾ seeking meaning units in the speech of the individuals that resulted in the themes and categories.

RESULTS AND DISCUSSION

The themes discussed led to the following categories: identification with the story; the relationship with the disease-health process; understanding of the text; and the disease-health process.

Identification with the story and the relationship with the disease-health process

This category combines the perceptions of how the children were able to identify themselves with the situation of the characters in the story. The characters take medications that taste like "olive oil", they discuss it, acknowledge the difficulty,

but continue treatment. The same situation was found in the children's statements.

How was Julia's and Peter's medication? (P. G1)

It tasted like olive oil. Both took the same medication. They took the same medication. (C2. G1)

I don't know [...]. My medication tastes bad, it is bitter. (C3. G3)

It tastes like cachaça. (C1. G1)

I remember [...]. It tastes sour, it wasn't nice. They didn't like taking it. (C4. G2)

I also take one that tastes bad. It is really bad. (C2. G2)

It is known that antiretroviral therapy is necessary and it is essential for the survival of those living with HIV. Therapy includes different medications that need to be ingested daily at different times. For children, the medications are available in solutions or pills. The solution is poorly accepted by many children due to its palatability, but the children need to take the medication, and when we discussed the topic, they spoke a bit about this experience.

A recent study with children with HIV/AIDS, conducted in Porto Alegre, showed that the children classify the antiretrovirals as: *unpleasant, a stinging feeling, sticks in the throat and has a horrible taste*⁽⁸⁾.

With regard to the continuous use of medications, normally only the family knows about it. The child learns to use the medication privately and also not to tell friends or classmates about it, even if they do not understand the real reason for the secrecy. When the secret is revealed, the concern is related to the trust in the other.

Who knows that you take medication? (P. G2)

My mom. My grandmother. My grandpa. My uncle and my other uncle. (C4. G2)

My mom. Only my mom and I. (C2. G2)

My mom and my cousin. My cousin K and C. She told her friends but she promised me that she would talk about it. (C5. G3)

My dad, my mom. My dad and mom also take it. (C3. G3)

A study on resilience showed that family and friends are significant protective factors to those who must face the disease and among their relationships, the family is the main source of support for HIV-seropositive people⁽⁹⁾.

Antiretroviral therapy contributes to the quality of life of those with HIV. However, the prolonged use of medication and the increasingly complex treatments impact the daily lives of children regarding their routines, their relationships, and their social life⁽⁸⁾, as shown by the statements below:

And at school, does anyone know about the medication? (P. G3)

No. (C3. G3)

No. (C2. G2)

No. Only the teacher (C4. G3)

If they do, they look at you in a different way. (C3. G3)

At school I keep quiet about it. I only told a girl, and the girl keeps the secret well. I told her. If I tell you a secret, will you talk about it? Then, I told her, and she didn't tell anyone. Then I asked everyone and they said "she didn't tell". (C5. G2)

For these children, who are unaware of their diagnosis, the concern is related to the use of medication, which has a certain meaning to them and cannot be revealed and this is learned at home when they attempt to discuss it with their family members, as described below.

Do you ask anyone at home about the medication? (P. G3)

I ask [...] I ask every day, why do I have to take it?; I wake her up and ask, and she says, it is because of your heart [...]. (C3. G3)

I ask if I am better or if I am not. I ask my mom something every day. (C5. G2)

My mom doesn't talk. (C3. G3)

Never? (P. G3)

Never. (C3. G3)

Secrecy is usually maintained, from the family's point of view, until the child is old enough

to understand what the disease is and when she is capable of taking care of herself, or when the family is prepared to talk about it⁽¹⁰⁾.

Although the issue of revealing the diagnosis is the focus of studies and discussed in the literature, there is no consensus on how to approach and explain complex issues of the therapy, such as confidentiality, stigma, the immune system, among other aspects, that could be clear enough for the children to understand their situation. The experience of the authors with this population has shown that. For these and other reasons such as fear of rejection, guilt and prejudice, the relatives of the children hide the real reason for treatment.

To reveal one's health condition to someone means having the courage to expose oneself and to perceive how the other person will accept and interpret the information. The fear of AIDS stigma is still very strong and inhibits people from taking action, particularly the relatives. Therefore, they also miss the opportunity of receiving support, which contributes to exclusion and prejudice⁽⁹⁾.

As for the blood tests, this is mentioned in the story when the character visits a friend in hospital. When the children were asked about the procedure, they expressed their perception of it.

Did the characters do blood tests in the story? (P. G1)

They did blood tests. He didn't cry. (C2. G1)

Peter took [blood]. (C3. G1)

He put something on his arm to take the medication and then he left the hospital, he was much better. I had to do a blood test to know if I had bacteria. (C1. G1)

They prick a needle in your arm. You can't cry to do the test. Oh teacher, I took it here [pointing to the arm]. (C4. G3)

I don't cry. (C3. G3)

I don't either. (C5. G3)

It can be noticed that the children express their feelings when they discuss their experiences through group discussions, i.e. the storytelling allowed moments to express their feelings.

It is known that the punctures are among the most stressful situations for the child, common in hospitals and outpatient clinics. A very peculiar way to minimize the stress caused by invasive

procedures is to use games to that allow them to express their feelings. In this case, the story played that role and also encouraged them to participate in their therapeutic process⁽¹¹⁾.

Another issue that was discussed when hearing the story was friendship. After family, relationships include friends. Friendship starts early in childhood and it is closely connected to games and playtime. The statements below show this.

[...] they are close friends, they are school friends, they go to school together, they are neighbors [...]. (P. G1)

They also play together. They ride their bikes. (C1. G1)

I have a friend. (C1. G1)

I have a [girl] friend. T. She is ten [years old]. (C4. G1)

My friends are A., T., and M (C5. G1)

They invite me to play with their toy pots. (C5. G1)

Just like any child, children with HIV play with their friends, develop skills and abilities, and must have the same opportunities for education and socializing.

The hospitalization of the character in the story, Peter, was another situation that aroused the curiosity of the children and because they identified themselves with him it brought back memories, as it is common in the lives of HIV-seropositive children due to opportunistic diseases. The statements of the children regarding the hospital were as follows:

Have you ever been hospitalized? (P. G3)

I was here [at this hospital]. (C5. G2)

Me too [ditto]. (C2. G2)

Did you stay here C4? (C5. G2)

[the child acknowledges by nodding her head]. I don't like being in hospital. (C2. G2)

Nor do I. (C4. G2)

I stayed a long time. (C1. G1)

I don't remember how old I was. (C2. G1)

When I was [hospitalized] I was six [years old]. (C5. G1)

I was 7. (C3. G1)

Hospitalization has different representations for the children other than those that they are accustomed to living. The environment is different from that to which she is accustomed to and she is surrounded by people who she does not know, who constantly touch her, talk to her, perform painful procedures, which makes the child anxious and afraid in many situations⁽¹¹⁾.

Another issue discussed in the story is the expectation about the future. The chapter was developed and written purposely to meet the children's expectations about their future, caring for themselves, and their life projects. The characters dream about a personal and professional future. The identification with the characters is shown below.

And about the future, what would you like to do? (P. G3)

I want to be a taxi driver [...]. Because I want to drive. (C3. G3)

Teacher. (C4. G3)

Doctor. (C5. G3)

Peter wants to be a driver [...]. Then he doesn't want to be one anymore [...]. He wants to date. (C3. G3)

He wants to be with Julia [character of the story]. (C5. G3)

He wants to be with Julia [ditto]. (C4. G3)

Nowadays, the future prospects of children with AIDS are different than at the beginning of the epidemic when they were born doomed to death. Therefore, this generation needs opportunities to discuss their future as they are teenagers or young adults who foresee many opportunities for the future as any other citizen⁽¹⁾.

With regard to sexuality, the story shows the romance between the characters Peter and Julia when they are teenagers. This situation stimulates their curiosity and conversations among the children.

Understanding the story and the disease-health process

This category examines the information conveyed by children without prejudice when playing

and listening to the story and learning by talking to colleagues, who contributed to their reflections. It can be inferred that they understood or at least started a process of real understanding of the health-disease process.

I take [medication] because of my chest. (C2. G1)

I don't know! (C3. G1)

I take the [medication] to keep well so I don't go to hospital. (C1. G1)

For my heart. (C3. G3)

When they state that they are unaware of their real disease, stating that the medication is for their chest, heart, among others, it shows how truly ignorant they are or that these are justifications accepted by them and their families, even if in a veiled way.

The partial revelation of the need for treatment and the disease itself is evident when some issues related to HIV are revealed to the children with goal of improving medication adherence and establishing a relationship of trust. Moreover, since the name of the disease has no meaning to the child, there is no need to disclose it. Thus, gradually the issues are disclosed until the time of telling them what is HIV/AIDS⁽¹²⁾.

The knowledge of the facts involving the disease affects the self-perception of the child when she comes to know the diagnosis. This can be positive when serious institutions such as schools and healthcare services help to clarify issues and lead to a less biased discourse⁽¹³⁾.

Retelling a story evoking memories is a shared experience that also leads to reflection. Children do that in an endeavor to understand the simultaneity of situations, the participation of others in the world, and the recollection of the experience varies according to their involvement in the collective experience⁽¹⁴⁾.

By sharing the experience of using antiretroviral drugs, they revived their experiences regarding treatment, which is critical to the effectiveness of therapy. The development of written material with professional help may be a good strategy for treatment adherence⁽¹⁵⁾. In addition, a story can also be an instrument that, together with other written materials, can improve medication adherence in the

case of children. While hearing and reading this story, one can use it in different ways, whether at the healthcare clinic or at home.

With respect to the process of diagnostic disclosure or even the need for medication treatment, the objects available, whether written, manipulated or when playing, need to contemplate the psychological condition of the child and the family or the professional must address issues that protect them from future prejudice.

With regard to secrecy, the statements were as follows:

Secrecy is when someone tells you something and you can't tell anyone because they will be upset with you and won't be your friend anymore. (C2. G2)

And when Peter and Julia arrive at school, there were lots of people. What did they do? (P. G2)

They didn't say anything. They waited for everyone to leave, then Peter told [...]. (C2. G2)

He couldn't say anything when he was around his friends. And not even to his friends where he lived. I didn't tell anyone. (C4. G3)

Now everyone will leave this room with a secret. (C5. G3)

Learning how to keep a secret in this condition is a strategy that can protect them. In this case, encouraging children to keep a secret about their treatment is also to look after them as society, unfortunately, still has prejudice against those with HIV, and it can be even more damaging for children to feel prejudice than for adults due to their cognitive immaturity. Choosing someone to whom you can tell and what to tell is a strategy that the children need to learn.

Building a strategy along with the professional who assists the child is the best way to reveal the diagnosis⁽¹³⁾. When the strategy is planned based on health education it can be of great value not only to the individual infected, in this case the child, but also to the family members, who are essential for psychological support⁽¹⁶⁾.

FINAL CONSIDERATIONS

The complexity of HIV/AIDS in children is still a major challenge for caregivers and health professionals. Addressing this issue among chil-

dren cannot be reduced to simple and easy situations, but at the same time, it must be easy to understand.

Thus, a story for children was written containing information about the health-disease process related to HIV. Several tests were conducted; many were discarded and recreated in an endeavor to refer to the children's life.

Therefore, the story "Peter's and Julia's Discovery: conversing about health and disease" was written and told during this study with the purpose of analyzing how it could contribute to the understanding of health-disease process of children with AIDS.

This study showed that it is possible to talk with children about their HIV status, without revealing the diagnosis, without lying, and still protecting them by using this story as a tool.

We expect that healthcare services can use this instrument to reveal treatment, diagnosis and serve as one of the actions for health education aimed at reducing prejudice and discussing treatment plans with the children and family.

For the child, the results may bring the following benefits: exercise actions toward health education, understand their health status, participate in the therapeutic process, adhere to treatment, and stimulate social interactions with other children who experience situations and realities similar to their own. The story also brings a direct contribution to the nursing practice and children because it can serve as an educational intervention to promote care.

We also expect that this study can inspire further studies, discussions at healthcare services and academic circles because, unlike many studies in which the results are based on data from adults, this study is based on the children's perceptions of the health-disease process related to HIV/AIDS.

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