



**OBJN**  
Online Brazilian Journal of Nursing

**ENGLISH**

Federal Fluminense University

**AURORA DE AFONSO COSTA**  
NURSING SCHOOL



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## The child experiencing the disclosure of the HIV/Aids condition: a interpretative study

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### ABSTRACT

**Aim:** to understand the experience of the process of disclosure of HIV/aids diagnosis in childhood. **Method:** we used a methodological referential theory based on data (PDT) and symbolic interactionism, with regard to research carried out between June and December 2012. The subjects were thirteen children and/or teenagers who were told about the diagnosis of HIV/aids. **Results:** Showed the perception of the children about a chronic disease condition, discovering by himself/herself, or about any health condition. **Conclusion:** the revelation of HIV/aids is a unique, dynamic and interactive process. However there isn't an ideal moment even when children indicate that this interaction should happen in childhood and/or at the time of their doubts and questions.

**Descriptors:** Diagnosis; Acquired Immunodeficiency Syndrome; HIV; Child; Adolescent; Nursing Care.

## INTRODUCTION

Human immunodeficiency virus infection and acquired immunodeficiency syndrome (aids) is a worldwide public health problem. Since its appearance, in 1980, it has gradually spread, and the modes of transmission of the human immunodeficiency virus (HIV) reveal a modified epidemiological profile<sup>(1)</sup>. The epidemic can be observed on the basis of the notification of the cases. In Brazil, from 1980 until June 2014, 491,747 (65.0% of the total) cases in men and 265,251 (35.0% of the total), in women. The South and Southeast regions make up 54.4% and 20.0% of the nation's total respectively. The state of Rio Grande do Sul offers one of the highest rates in children under five years of age: in 2013, there were 6.2 cases for every 100,000 inhabitants and adults, a rate of 41.3 cases for every 100,000 one hundred thousand inhabitants<sup>(1)</sup>. AIDS is a chronic disease, with new perspectives of health that will have implications for the future, due to the transition from childhood to adolescent children who have HIV/aids by vertical<sup>(2)</sup> and horizontal<sup>(1,3)</sup> transmission. Aids in childhood and adolescence represents a major health problem. Waiting for the opportune moment for revelation, in many cases, ends up resulting in distrust and discovery for the child, through listening to conversations in the family, at school, in the health service, or the media. Avoiding and not talking about the diagnosis may engender conflicts within the child, as regards autonomy of care, at school, at the beginning of their sexual life, in adherence to treatment<sup>(2)</sup>. The most appropriate time to tell about the disease has been of concern to health professionals and families. From the reality experienced by the child, one wonders: How did the disclosure process of HIV/aids condition occur in childhood? This

leads to the objective of understanding the meaning of experiencing the process of disclosure of the HIV/aids condition in childhood.

## METHOD

Qualitative study based on symbolic interactionism-IS<sup>(3)</sup>, using theoretical and Grounded Theory as a methodological frame<sup>(4)</sup>. The study took place in the Infectious Diseases Clinic of a University Hospital in the State of Rio Grande do Sul, Brazil. The study was conducted in school with 13 year old children and teenagers aged between 11 and 16 years, who had been made aware of their diagnosis between the ages of 5 and 12. The interviews were conducted by the guiding questions: what was it like for you to know that you had a disease? What did you feel when you heard that you had a disease? Data were collected and analyzed in a systematic and comparative way as advocated by Grounded Theory<sup>(4)</sup>, between August and December 2012, after approval by the Ethics on Research Committee at the Universidade Federal de São Paulo under paragraph 60692 of 8/13/2012.

## RESULTS

The results showed the perception of the child with regard to having a chronic disease, who discovered the condition by herself/himself, or of the need to adhere to treatment. The revelation of this diagnosis should be done a singular and gradual form, according the emergence of questions by the children; the sooner reveal the diagnosis the easier will be the adaptation of them. In addition, with the advance of time, the more complex will be her/his acceptance, in particular during

adolescence, due to the conflicts inherent in the individual at that age.

## DISCUSSION

Several situations can trigger the beginning of the revelation of the diagnosis of HIV/aids to the child, such as the media and the school environment. The permanent monitoring of their condition, consultations, tests and medications, also contribute to the child being wary and asking about what's going on. Opportunistic infections, involving treatment and hospitalization, culminate in the search for explanations. Some families<sup>(2,5)</sup> choose not to reveal the diagnosis of HIV/aids by judging that the child does not have sufficient maturity and how prejudices protection mode.

## CONCLUSION

The revelation of the diagnosis of HIV/aids in childhood, is a process that requires discussion and understanding following the first questioning of the child. The research data showed that there is no protocol or recipe in relation to the disclosure of the diagnosis, because each individual reacts in a unique way, due to the story of their life, of values and family behavior, as well as factors inherent in their own development. The fact of living with a disease of which the individual is not advised/may ask about and not receive explanations, can encourage the development of concepts/prejudices. This may be in addition to the pain of realizing that something is going on and it is about something about which the individual can't talk and ask,

because if s/he does, it will cause pain to the family. The revelation of the diagnosis is a complex process that needs to be permeated by dialogue, by the interaction and the links between families and health professionals. Children have shown that not revealing the diagnosis early may bring about negative consequences, particularly in adolescence.

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**Original Reference:** Freitas, Hilda Maria Barbosa. Montando um quebra-cabeça para compreender o que tem e seguir com a vida: a criança vivenciando a revelação de ter HIV/AIDS. Hilda Maria Barbosa Freitas. - São Paulo, 2014.

**Defense date:** 10 de dezembro de 2014.

**Examination Board:** Dra. Maria da Graça Corso da Motta, Dra. Stela Maris de Mello Padoin, Dra. Conceição Vieira da Silva-Ohara, Dra. Giselle Duppas.

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All authors participated in the phases of this publication in one or more of the following steps, in According to the recommendations of the International Committee of Medical Journal Editors (ICMJE, 2013): (a) substantial involvement in the planning or preparation of the manuscript or in the collection, analysis or interpretation of data; (b) preparation of the manuscript or conducting critical revision of intellectual content; (c) approval of the versão submitted of this manuscript. All authors declare for the appropriate purposes that the responsibilities related to all aspects of the manuscript submitted to OBJN are yours. They ensure that issues related to the accuracy or integrity of any part of the article were properly investigated and resolved. Therefore, they exempt the OBJN of any participation whatsoever in any imbroglios concerning the content under consideration. All authors declare that they have no conflict of interest of financial or personal nature concerning this manuscript which may influence the writing and/or interpretation of the findings. This statement has been digitally signed by all authors as recommended by the ICMJE, whose model is available in [http://www.objnursing.uff.br/normas/DUDE\\_eng\\_13-06-2013.pdf](http://www.objnursing.uff.br/normas/DUDE_eng_13-06-2013.pdf)

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Received: 06/10/2015  
Revised: 06/23/2015  
Approved: 06/23/2015