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Disclosure of the diagnosis of parental HIV

Bruna Pase Zanon¹, Pâmela Batista de Almeida², Crhis Netto de Brum³, Cristiane Cardoso de Paula⁴, Stela Maris de Mello Padoin⁵, Alberto Manuel Quintana⁶

Abstract

The aim was to assess scientific evidence available in the literature about the factors that influence the decision to disclose the parents' HIV diagnosis to their children. The type study is integrative review in the Medline and Lilacs databases, using the words [HIV or aids] and [criança or adolescente] and [revelação]. 14 articles were selected. Factors influencing the decision to disclose the diagnosis were: the cognitive ability and maturity of the child, the strengthening of family ties, the information provided to the child about the disease, parental illness and death, the discovery by third parties, stigma and prejudice, negative reactions from the children, the way to talk about the disease with the child, and the fear of losing parental power. Therefore, a process of preparation for disclosure of the diagnosis, shared among family members who take care of the child and health professionals who maintain ties with the family, was identified.

Keywords: HIV. Acquired immunodeficiency syndrome. Child health. Adolescent health. Truth disclosure. Family.

Resumo

Revelação do diagnóstico de HIV dos pais

Este artigo tem o propósito de avaliar evidências científicas, disponíveis na literatura, acerca dos fatores que interferem na decisão de revelar o diagnóstico de HIV dos pais para os filhos. Trata-se de revisão integrativa, desenvolvida nas bases de dados Medline e Lilacs, utilizando os termos [HIV or aids] and [criança or adolescente] and [revelação]. Selecionaram-se 14 artigos. Os fatores que interferem na decisão de revelar o diagnóstico foram: capacidade cognitiva e maturidade da criança; fortalecimento dos laços familiares; informações para a criança acerca da doença; adoecimento e morte dos pais; descoberta por terceiros; estigma e preconceito; reações negativas da criança; modo de falar da doença com a criança; e medo de perder o poder parental. Portanto, indica-se preparo para revelação do diagnóstico, de modo compartilhado entre os familiares que cuidam da criança e os profissionais de saúde que mantêm vínculo com essa família.

Palavras-chave: HIV. Síndrome da imunodeficiência adquirida. Saúde da criança. Saúde do adolescente. Revelação da verdade. Família.

Resumen

Revelación del diagnóstico de VIH de los padres

El objetivo de este texto fue evaluar la evidencia científica disponible en la literatura sobre los factores que influyen en la decisión de revelar el diagnóstico de VIH de los padres a los hijos. El tipo de estudio es una revisión integral en las bases de datos Medline y Lilacs, utilizando las palabras [HIV or aids] and [criança or adolescente] and [revelação]. Se seleccionaron 14 artículos. Los factores que influyen en la decisión de revelar el diagnóstico fueron: la capacidad cognitiva y la madurez del niño; el fortalecimiento de los lazos familiares; informaciones para el niño acerca de la enfermedad; enfermedad y muerte de los padres; descubrimiento por parte de terceros; estigma y prejuicio; reacciones negativas de los niños; modo de hablar sobre la enfermedad con los niños; y, miedo a perder el poder parental. Por lo tanto, se recomienda una preparación para la revelación del diagnóstico, de modo compartido entre los familiares que cuidan al niño y los profesionales de salud que mantienen vínculos con esa familia.

Palabras clave: VIH. Síndrome de inmunodeficiencia adquirida. Salud del niño. Salud del adolescente. Revelación de la verdad. Familia.

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Declararam não haver conflito de interesse.

AIDS globally constitutes a public health problem because, from the first cases reported in the 1980s, it has been continuously disseminated, with repercussions on individuals, families, society and public policy¹⁻³. In the course of the epidemic, it showed quantitative changes, regarding the progression of reported cases, as well as qualitative changes, relating to the increased number of affected females, youth, impoverished people and rural populations, in its epidemiological characteristics^{4,5}. Concerning health care for HIV-infected people, Brazil has maintained universal and free access policies to antiretroviral therapy (ART) since 1996, an initiative that provides a greater perspective of quality of life⁶, allowing those infected to maintain their life projects, such as creating and expanding a family.

From the perspective of AIDS in a family, it is emphasized that HIV-infected children were mostly exposed to vertical transmission⁴, and their parents therefore were also HIV positive^{7,8}. There are many clinical and social challenges experienced by parents and children, as well as by the professionals who provide health care to this population^{9,10}. Among the clinical demands are mainly: permanent monitoring of health and adherence to drug treatment^{6,11}.

The social impact of HIV status involves the family support network both for emotional support to parents and for children's daily care demands^{8,12}. In most cases, this network is restricted due to the concealment of the diagnosis, related to fear of prejudice arising from the associated stigma of the social response to the epidemic^{13,14}.

Among the challenges faced by families, the disclosure of the diagnosis of parents' HIV status for their children stands out. It is a process influenced by factors related to the family and to the child, as well as to society and health professionals. It requires the involvement and availability of those involved in children's and adolescents' health. Disclosure of the diagnosis can bring many benefits, but there are family members who are afraid that children will not be fully prepared to understand and handle it¹⁵⁻¹⁸, leading the family to delay disclosure. In this context, this study has as its objective the evaluation of scientific evidence available in the literature regarding the factors that influence the decision to disclose the diagnosis of parental HIV to children.

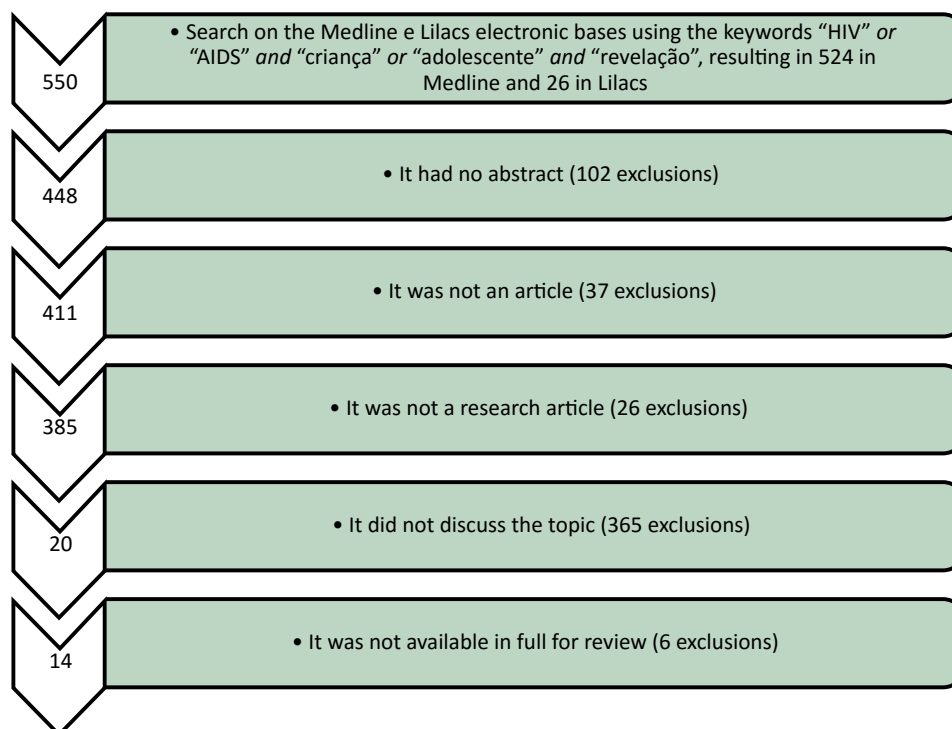
Methodology

This is an integrative review study that aims to systematize the literature¹⁹ searching for evidence

that answer the question: "What are the factors that influence the decision to disclose the diagnosis of parental HIV to children?". A literary survey was conducted by accessing the Medical Literature Analysis and Retrieval System Online (Medline) and the Latin-American and Caribbean System on Health Sciences Information (*Latin American and Caribbean Health Sciences* - Lilacs) electronic databases, using the terms [HIV or AIDS] and [children or adolescents] and [disclosure]. The search was undertaken in March 2015. The following inclusion criteria were used to select the *corpus*: abstracts available in the database; research articles; topics about disclosing the diagnosis of parental HIV to children; articles available online in full and for free; available in Portuguese, English or Spanish. In order to capture the largest possible number of articles that answered the research question, a time frame was not established. Among the 550 scientific papers identified in the databases, 14 were selected as shown in the flowchart with the criteria for inclusion (Figure 1).

This selection flowchart was executed independently by two researchers, in order to diminish any inclusion bias. When there was no consensus, a third investigator (study supervisor) has been consulted. Extraction documentary forms were used for the 14 studies selected²⁰. An evaluation of the evidence's strength was developed and evidence was classified according to seven levels: Level I - evidence produced through systematic review, or meta-analysis of randomized controlled trials, or clinical guidelines based on systematic reviews of randomized controlled clinical trials; Level II - evidence derived from at least one randomized controlled clinical trial, clearly delineated; Level III - evidence from well-designed clinical trials without randomization; Level IV - evidence from cohorts and well-designed case-control studies; Level V - evidence originating from the systematic review of descriptive and qualitative studies; Level VI - evidence derived from a single descriptive or qualitative study; Level VII - evidence originating from authorities' opinions and/or reports from expert committees²¹. The descriptive analysis indicated the synthesis of each publication and comparisons of the main results that answer to the research question. As for the ethical aspects, the definitions, considerations and assessments used by the authors of the selected primary studies have been respected and presented faithfully.

Figure 1. Flowchart with the criteria for inclusion of articles in the review study regarding the disclosure of the diagnosis of parental HIV to children. Lilacs and Medline, 2015



Results and discussion

As for the characterization of the articles analyzed, there was a predominance of studies conducted in African countries ($n = 7$), followed by the US ($n = 6$) and India ($n = 1$). In the area of knowledge, there was a concentration of medical articles ($n = 6$), followed by psychology ($n = 5$) and multi-professional ($n = 3$). There was increasing investment in the quantity of publications on the topic of disclosure of HIV diagnosis, with a concentration in the last two three-year periods: 2000-2002 ($n = 3$), 2003-2005 ($n = 1$), 2006-2008 ($n = 1$), 2009-2011 ($n = 5$) and 2012-2014 ($n = 4$). Regarding design, there was a predominance of qualitative studies ($n = 8$), followed by non-experimental quantitative studies ($n = 4$), a quantitative and qualitative study ($n = 1$), and a randomized clinical study ($n = 1$). Regarding the classification of the evidence, there was a predominance of level 6 studies ($n = 9$), followed by level 4 studies ($n = 4$) and a level 1 study ($n = 1$).

This research identified the following scientific evidence of factors that influence the decision to disclose parents' HIV diagnosis to children: cognitive ability and maturity of the child; strengthening of family ties; informing children about the disease;

parents' illness or death; the possibility of discovery by third parties; stigma and prejudice; negative reactions by children; the way of speaking about the disease to the child; and fear of losing parental power²²⁻³⁵ (Table 1, appendix).

The studies showed that parents waited until their children become mature enough to understand an explanation of their HIV diagnosis^{32,33}, and that disclosure of the diagnosis should happen when parents realize that children are able to understand and cope with the diagnosis of parental HIV²². Older children^{24,27,34,35}, in early adolescence^{30,32} and between the ages of 14²⁸ and 18^{30,33,34} were more likely to understand the condition of their parents.

According to cognitive theory, development can be considered a process of successive changes, both qualitative and quantitative, of cognitive structures. These changes take place in stages (sensory-motor, pre-operational, concrete operational, formal operational) that follow more or less determined ages (0-2 years, 2-7 years, 7-11 years, 12 onwards, respectively). Highlighting the last two stages, it is understood that between 7 and 11 years children develop notions of time, space and causality, being able to relate different aspects and abstract data from reality. From 12 years onwards, cognitive

structures reach their highest level of development and children become able to apply logical reasoning³⁶. Thus, it is possible to understand this reference to certain ages for disclosure of the diagnosis, as noted by the evaluation that parents make of children's ability to understand the diagnosis that needs to be communicated within the family.

The first stage (0-2 years) corresponds to the phase in which children do not have the mental capacity and their thinking is diffuse, making the absorption of rules difficult (anomie). The second and third stages (2-7 years and 7-11 years) corresponds to the phase in which children follow the rules set forth by others, internalizing guidelines and questioning little (heteronomy). The fourth stage (12 years onwards) is the phase in which children relate to the established rules and suggest new ones, building agreements, in view of their ability to critically reflect (autonomy)³⁶. This view supports the experience of parents waiting for their children to be able to understand and cope with the diagnosis to make the disclosure. However, not disclosing the diagnosis to children, even before their cognitive ability to understand the situation, restricts their autonomy.

Disclosure can be understood as an opportunity to strengthen ties between parents and children, as it promotes better communication about AIDS among them^{30,32}, improves family relationships and children's understanding of roles and responsibilities³⁴, helps to understand the parents' situation³⁵ and favors rapprochement between parents and children, as a positive result of the disclosure³⁰. This communication between parents and children, even when it comes to bad news, is important for the family's well-being and relationship. What is understood as "bad news" is that which adversely affects the patient's vision of the future, involves a threat to one's physical and/or mental well-being, and reduces the possibility of choices in the immediate or future life³⁷.

Parents disclosed their condition to their children as a way to educate them about the disease, so that they can take care and avoid being infected with HIV³⁴, by providing information regarding the prevention of risk behavior³⁴. However, conceptions of death can lead parents to postpone disclosure, because they believed that knowing the HIV diagnosis, the children might think that their parents were dying²². Mothers expressed concerns, including the fears that the child can have regarding HIV and death³⁴, and consider the disclosure a preliminary

step to making arrangements for the child's future in case of incapacity or maternal death²².

The illness of the parents is a reason that leads them to disclose their diagnosis, and relates to the need to ensure childcare should they die^{23,25,29,35}. Parents with more serious diagnoses were more likely to tell their children^{23, 24, 29} and realized the need for their children to know why their parents become ill²⁵. Declining health or physical appearance were factors associated with the disclosure of the diagnosis²². The fear of death when parents become ill is associated with the high mortality of the disease before the advent of effective antiretroviral treatment, and persists even if nowadays AIDS is considered a chronic health condition.

An aspect that has led parents to postpone disclosure was the possibility of discovery by third parties, as parents fear that children would not be able to keep it secret, revealing their condition to other people and, thus, exposing their parents lives^{27,30,34}. Parents who delayed the disclosure also had intended to protect their children from the stigma and discrimination related to HIV^{22,26,33}, because they fear that, if the parents of other children found out that they have HIV, they would no longer allow their children to play together³⁰. Moreover, they are afraid of being stigmatized or discriminated against by their own children³³. Communication difficulties occur in any relational situations, especially when they involve illness and death. In this particular situation, they are further compounded by the stigma of AIDS, in addition to the vulnerabilities of children and adolescents and to the limitations of families to face the challenge of disclosure, as well as professional preparedness (or lack thereof) to provide support.

The creation of negative feelings in children has contributed to delaying disclosure. Parents describe fear of hurting their children³⁰ and that they may react negatively to disclosure³³, they fear that children could be shocked and embarrassed²⁶. They fear feelings of rejection, hatred and guilt³². Parents wanted to somehow protect children from concerns and fears^{30, 35}, considering that knowing about the disease would be very painful for the child^{26,29,30,33}. The most common adverse reactions of children after the disclosure of paternal diagnosis was fear regarding their parents' state of health and life, and fear of being stigmatized by friends³⁰. After disclosure, children can become frightened and shocked³¹.

How to disclose was a common stumbling block/obstacle, because parents did not know how

to approach the subject. Parents were afraid that they might be asked questions they would not be able to answer³³⁻³⁵, and that they would not be able to adequately describe the disease³⁰. As regards to how this process develops, the act of informing boils down to the initial moment of disclosing the disease. However, all information should be included in the communication between parents and children, passing through the various moments faced by both during the process of disclosure. Communication can also be associated with professional support and sharing among those involved.

The fear of losing parental power, the respect of their children, or that their own children might form negative judgments about them^{32,33}, is shown as another cause leading to the postponement of disclosure. Knowing that their parents are HIV-positive, some children may consider them unable to take parental responsibilities³². It has been reported that some children began to have relationship problems with their parents after becoming aware of their HIV status³². It is possible to believe that the problems derive, predominantly, from paternalistic relationships, with interference in the child's and/or adolescents' autonomy.

The discussion regarding children's autonomy and right to know about the diagnosis involves ethical issues, and for each of the principles there are pros and cons. Therefore, the specifics of each case play important roles in balancing these issues. It is noteworthy that the principle of autonomy may dictate that children have the right to know certain diagnosis. However, from an ethical point of view, children are able to agree, but not to consent, and parents have rights and responsibilities in the care of their children. The principle of beneficence indicates that disclosure could increase the children's sense of autonomy, enhancing their ability to care for themselves, and reduce the anxiety of the unknown, minimize resentment for being kept in ignorance, and enable open communication in the family. The principle of non-maleficence points to concerns, for example, regarding children feeling different from others or disclosing the diagnosis to

third parties, exposing themselves and their families to the possibility of discrimination. Therefore, it is understood that, from the cognitive point of view, children may not have the ability to understand the diagnosis of HIV and its implications, in which case disclosure may cause damage³⁸.

Finally, results of the association between knowledge of the diagnosis and the Child Behavior Checklist scores showed that the presence of the clinical classification (HIV-positive) for mental health problems and social problems is associated with concealment of the diagnosis. This data contradicts the caregivers' premise of delaying the disclosure of the diagnosis to avoid emotional damage³⁹.

Final considerations

Studies have shown that several factors contribute to disclosure of the parents' diagnosis to their children. Therefore, the importance and the need to prepare parents for this revelation, which becomes more effective when shared with health professionals, is highlighted. This preparation, following the concept that disclosure is a process that culminates at the time of the announcement itself, needs to be covered by the strategies guided by the discussion of the benefits of disclosure, in order to minimize the negative factors and enhance the families' attributes. It is also recommended that support strategies be developed for parents and children, because of the possible repercussions following disclosure of the diagnosis.

Gaps in the production of knowledge were: lack of description of the place of disclosure, how is the family relationship between parents and children in this process, how parents' preparation for the disclosure was developed and its repercussions. Therefore, it is necessary to invest in research with outlines that present strong evidence regarding the topic investigated, especially in the practice of health care. It is also important to make efforts to empower health teams to help parents experience this delicate process in the best possible way.

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Participation of the Authors'

This manuscript is part of the results of Pâmela Batista de Almeida's Master in Nursing dissertation. The work was supervised by Dr. Alberto Quintana and co-directed by Dr. Cristiane Cardoso de Paula. Doctoral student Bruna Pase Zanon helped in the organization of the results and in the discussion. Dr. Stela Maris de Mello Padoin was part of the dissertation examination board, contributing to the enhancement of the work, and doctoral student Crhis Netto de Brum contributed in the critical review of the manuscript.

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Appendix

Table 1. Extraction of data from the articles included, relating to the disclosure of the diagnosis of parental HIV to children. Lilacs and Medline, 2015

Reference	Objectives	Methodology	Results	
			Favoring factors	Unfavorable factors
Pilowsky, Sohler, Susser ²²	To understand the reasons given by mothers with AIDS to disclose, or not, their diagnosis to their children	Qualitative: 29: mothers living in one of two facilities in New York that provide accommodation and medical treatment for adults with AIDS	• Appropriate age of child • Declining health or physical appearance of parents • Fear of death	• Stigma and discrimination • Concern for children's feelings
Armistead, Tannenbaum, Forehand, Morse, Morse ²³	To provide information to families affected by HIV and professionals on how to make decisions related to the disclosure	Qualitative: 87 African American HIV-infected mothers and their uninfected children	• More serious diagnosis • Increased social network * Older children	Did not produce any result of factors that disfavor the disclosure.
Lee, Rotheram-Borus ²⁴	To examine the impact of the disclosure of the parent's HIV diagnosis to all adolescent children	Quantitative: representative cohort of parents living with HIV (n = 301) and their children (n = 395) in five years	• More serious diagnosis • Older children	Did not produce any result of factors that disfavor the disclosure.
Nöstlinger, Jonckheer, Belder, Wijngaerden, Wylock, Pelgrom <i>et al.</i> ²⁵	To identify the number of parents or caregivers in a sample of people living with HIV in Flanders, the number of children affected by HIV, and the specific characteristics related to their families	Quantitative and qualitative: 628 patients from three reference centers for AIDS	• More serious diagnosis • Prior knowledge by other family member	• Concern for children's feelings
Rwemisisi, Wolff, Coutinho, Grosskurth, Whitworth ²⁶	To assess parents' attitudes and current counseling policy and practice regarding children testing parental disclosure in Uganda before antiretroviral therapy	Qualitative: 10 HIV-positive parents recruited from The AIDS Support Organization (TASO)	• Appropriate age of child (average age 18)	• Concern for children's feelings • Fear of stigma • Fear that the child may find out via third parties, other than family members
Thomas, Nyamathi, Swaminathan ²⁷	To explore perceptions and needs from mothers living with HIV to address the challenges regarding their behavior in search of health, fears around disclosure, and issues related to stigma and discrimination	Qualitative: 60 HIV-infected mothers recruited through a large maternity hospital and a STD clinic in Chennai, India	• Appropriate age of child	• Fear that the child cannot keep it secret

Reference	Objectives	Methodology	Results	
			Favoring factors	Unfavorable factors
Delaney, Serovich, Lim ²⁸	To explore the psychological differences among HIV-positive women who revealed their diagnosis to all, some or none of their biological children	Quantitative: 90 women with their children	• Appropriate age of child (on average to 14.6 years)	Did not produce any result of factors that disfavor the disclosure.
Nam, Fielding, Avalos, Gaolathe, Geissler ²⁹	To relate adherence to antiretroviral therapy with the disclosure of parental HIV diagnosis to their children	Qualitative: 21 HIV-positive patients on antiretroviral therapy in Botswana	• More serious diagnosis; • Prior knowledge by other family members	• Insufficient/ Inappropriate age of child; • Concern for children's feelings
Kennedy, Cowgill, Bogart, Corona, Ryan, Murphy <i>et al.</i> ³⁰	To retrospectively describe the learning process of children whose parents were HIV positive	Qualitative: 33 HIV-infected parents, 27 of their minor children, 19 adult children and 15 caregivers	• Appropriate age of child (between 7 and 18 years); • Improve the relationship with parent	• Concern for children's feelings • Fear of stigma • Fear that the child may discover through others • Stigma and discrimination
Murphy, Armistead, Marelich, Payne, Herbeck ³¹	To evaluate the Teaching, Raising, and Communicating with Kids (TRACK) program as a pilot longitudinal intervention to help mothers living with HIV to disclose their diagnosis to their young children (6 to 12 years)	Quantitative: 80 dyads	Did not produce any result of factors that favored the disclosure.	• Concern for children's feelings
Kyaddondo, Wanyenze, Kinsman, Hardon ³²	To examine moral dilemmas and pragmatic incentives surrounding the disclosure of HIV status in Uganda	Quantitative: 148 HIV positive people	• Appropriate age of child (early teens) • Moral obligation to inform the children in order to transfer family responsibilities or to request support	• Fear of losing parental power and children's respect • Scapegoating • Feeling of hate for the parents after the disclosure • Concern for children's feelings
Madiba ³³	To examine the social context that influences disclosure of parents' HIV status to children, from the perspective of parents who access a university hospital in South Africa	Qualitative: 26 non-biological parents of children aged 7 to 18 years	• Appropriate age of child (average age 18) • Prevention of risk behavior • Improving communication regarding AIDS between parents and children	• Fear of difficult questions • Fear that the child cannot keep it secret; • Concern for children's feelings • Lack of parents' preparation • Fear of losing the respect of children or of their judgement • Fear of being discriminated against by their own children

Reference	Objectives	Methodology	Results	
			Favoring factors	Unfavorable factors
Rochat, Mkwanzazi, Bland ³⁴	To describe the development of structured intervention focused on the family to support mothers in disclosing their HIV diagnosis to their HIV-negative children in rural South Africa, which is an area with high HIV prevalence	Qualitative: 24 Zulu families, all mothers were HIV positive and a child, HIV negative	• Appropriate age of child (between 10 and 18 years) • Improvement in family relationships and understanding of roles and responsibilities • Increased/Increase in health promotion activities • Improved confidence of parents in health promotion and sex education • Increased discussion of risks to children including bullying, problems with teachers, physical and sexual abuse	• Fear of difficult questions concerning the source of HIV infection or death • Fear that the child cannot keep it secret
Tiendrebeogo, Hejoaka, Belem, Compaoré, Wolmarans, Soubeiga <i>et al.</i> ³⁵	To analyze if parents disclose their HIV status to their children, the reasons for disclosure, how they proceed and how children respond	Qualitative: 63 parents of 7 year old children who had been in treatment for more than three years in two major cities in Burkina Faso	• Appropriate age of child (older) • Empathy for parent's situation • Preliminary step towards making arrangements for the child's future, in case of maternal incapacity or death	• Maternal concern regarding as to how children will deal with death and dying; • Indications that the child may not understand what is said; • Desire to protect the child from painful concerns