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Costs and benefits of secrecy: the dilemma experienced by adolescents seropositive for HIV

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ABSTRACT

This study explored the experiences of the first generation of adolescents who acquired HIV through vertical transmission when disclosing their diagnosis to friends and romantic partners. The study sample was selected by convenience, with 20 patients (13–20 years old) participating in a qualitative investigation using individual interviews (language: Portuguese; duration: 45 minutes). The participants were followed in specialized clinics for the treatment of pediatric AIDS in São Paulo, Brazil. The results suggest that families who live with HIV tend to keep it a secret, and such behavior is learned and accepted unquestioningly as natural. Respect for privacy and the fear of rejection, coupled with the belief that information about their disease will be spread, are the main beliefs with which participants justify their secrecy. In terms of romantic relationships, adolescents were aware that their HIV status should at some point be shared with current or future sexual partners. However, the decision to reveal an HIV diagnosis in romantic relationships is permeated by anxieties, uncertainties about the right time, and fear of abandonment. In any case, telling the truth requires trust, guarantees of the other's love, and, in some cases, probing romantic partners beforehand to learn their perceptions about the disease. Participants who had experiences disclosing their HIV status shared positive and negative results, including emotional support, acceptance, and understanding, along with ostracism, discrimination, and abandonment by family members. The findings of this paper reinforce the challenges of revealing an HIV diagnosis to third parties. It requires understanding the meaning and importance of the secret for each patient, along with the conflict between the right to confidentiality and the responsibility of treating others exposed to the disease. All these aspects should be discussed extensively with this population and incorporated into clinical practice.

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Introduction

The dynamic of secrecy that surrounds adolescents infected with HIV through vertical transmission has acquired new meaning in the last decade. They ceased to be the causes of the secret, that is, those from whom the disease was hidden over the years, and became its keepers. This new psychosocial configuration is not a simple process, because revealing an HIV-positive status can leave the individual in question vulnerable to stigma and discrimination, characteristics also identified in the population of adults living with HIV/AIDS (Hosek, Harper, & Domanico, 2000).

Most studies about the disclosure of HIV diagnosis in pediatric AIDS clinics focused on describing the benefits

of such disclosure and the barriers that prevent caretakers from accepting this process (Galano, De Marco, Succi, Silva, & Machado, 2012). However, there are few reports that analyze strategies used by teenagers to reveal their disease to others.

Siu, Bakeera-Kitaka, Kennedy, Dhabangi, and Kambugu (2012) identified that participants named countless reasons to justify their maintenance of secrecy, and some of these are similar to those of adults. In general, they mention fear of prejudice, rejection, and social isolation (Ateka, 2006; Brou et al., 2007; Fernet et al., 2011; Kadowa & Nuwaha, 2009).

It is known that non-disclosure of stigmatizing diseases is higher in countries with limited resources (Vreeman, Gramelspacher, Gisore, Scanlon, & Nyandiko,

2013). In Brazil, the dynamics of stigma production related to HIV/AIDS is intensified by social inequality, but there is a lack of local studies (Monteiro & Villela, 2014).

The goal of this study was to access the experiences of perinatally HIV-infected teenagers when disclosing their diagnosis to friends and partners. The novelty of this work lies in attempting to understand the feelings involved in revealing this secret. This comprehension can contribute to the improvement of holistic care for this population.

Methods

In April 2009, researchers from Brazil, Canada, and France, participated in the Adoliance project, an international scientific cooperation. This project examined psychosocial factors related to the life experiences of 268 adolescents seropositive for HIV, using quantitative and qualitative approaches to research. The qualitative phase, carried out in November and December 2011, involved 20 out of 268 adolescents (13–20 years) who participated in an interview with questions related to the process of HIV disclosing to third parties (language: Portuguese; duration: 45 minutes). To determine when to stop interviews, the criterion of data saturation was employed (Morse, 1995; Turato, 2003). The interviews were recorded with the consent of the teenagers and subsequently transcribed and analyzed using the content analysis technique: exhaustive reading of interviews, organization of the main ideas, and creating categories and subcategories (Bardin, 2011). In order to facilitate data organization, the software Solutions Qualitative Research (QSR) International Nvivo 9 was used.

The study was approved by regulators and the Brazilian National Ethics Committee. Informed consent was obtained from the parents and/or guardians.

Results

The sample consisted of 20 adolescents with a mean age of 17 (Table 1).

Table 2 lists these teenagers' experiences disclosing an HIV diagnosis to third parties, the motivations to revealing their disease, and the reactions of those with whom the secret was shared.

Analysis of interview material allowed the development of three broad categories: living with the secret; the secret in romantic relationships; secret: to keep it or not? The subcategories that emerged in each theme are shown in Table 3.

Table 1. Distribution of the adolescents' sociodemographic characteristics.

Characteristics		Population (n = 20)	
Gender	Female	11	
	Male	09	
Age group (years)	13–15	Boys	Girls
	16–18	03	05
	19–20	05	03
Schooling (years of study)	5–8	07	
	9 and up	13	
Race/Color (self-reported)	White	08	
	Black	01	
	Mulattos	11	
Religion	Yes	18	
	No	02	
Who they live with	Father and/or mother	12	
	Other family members	06	
	People outside the family	01	
	Institution	01	
Orphanhood	Father	04	
	Mother	08	
	Father and mother	03	

Table 2. Categories and subcategories of disclosing an HIV diagnosis to third parties.

Categories	Subcategories
Living with the secret	<ul style="list-style-type: none"> The secret across generations The right to privacy
The secret in romantic relationships	<ul style="list-style-type: none"> The Responsibility to reveal the secret Dilemmas: When and how to tell a sexual partner about HIV?
Secret: to keep it or not?	<ul style="list-style-type: none"> Motivations to tell Benefits costs and of the secret

Table 3. Behavioral patterns of disclosing an HIV diagnosis to third parties.

Questions		Boys (n = 09)	Girls (n = 11)
Did you tell anyone?	No	5	5
	Yes	4	6
Total		9	11
Whom?	Boyfriend/girlfriend	1	3
	Friend	2	4
	Seropositive friend	1	–
	Boss	1	–
Total		5	7
Reaction of those told	Positive	5	5
	Negative	1	1
Total		6	6
Why did you tell?	Loyalty, guilt about keeping the secret	–	2
	Justifying absences at work	1	–
	Moment of sadness/despair	–	2
	Questions by a friend	1	–
	Questions by or suspicion of sexual partner	–	1
	Questions about medications	–	2
	Moment of impulsiveness	1	–
	Health concerns	1	–
		4	7
Total		4	7

Living with the secret

Despite being considered an element of the private life of individuals living with HIV/AIDS, issues related to the illness are not discussed even within family.

For them and for me it's like I don't have it ... and I don't talk about it with my father or stepmother. (Female, 15 years)^c

(1) The Secret Across Generations

In this study, the adolescents have frequently been taught by parents that they should conceal everything related to their treatment in order to protect themselves against the stigma associated with HIV.

I never had the courage to tell. I think there's no need to tell, just like I was taught by my parents ... (Female, 18 years)

In this family context, keeping an HIV-positive status hidden is a practice accepted without question.

(2) The Right to Privacy

There are some caregivers who gave information about the disease to close friends, church pastors, or teachers. The adult's decision to disclosure, in lieu of the teenager, can cause discomfort and a feeling of intrusion.

I never told, just my aunt ... She told them my story, all of it ... (Male, 17 years)

The secret in romantic relationships

(1) The Responsibility to Reveal the Secret

Sharing HIV status with partners is a permanent concern for all the interviewees. Revealing HIV-positive status is a desire for a partnership, but there is the possibility that the other person chooses whether or not they are willing to live with a seropositive partner.

If I want a future with somebody, she has to know ... because she has the risk of becoming infected! (Male, 17 years)

(2) Dilemmas: When and How to Tell a Sexual Partner About HIV?

Breaking the barriers of silence is not a simple process, because they served as protection against possible aggression from the social environment.

Feeling loved, trusting the other enough to tell, and a guarantee that the other will keep the information secret are vital for disclosing.

I think that to tell someone, a boyfriend, you have to be sure that he loves you. (Female, 20 years)

Secret: to keep it or not?

(1) Motivations to Tell

The adolescents felt motivated to reveal the disease by being pressured through questions from friends, in moments of sadness or due to the guilt caused by hiding the truth from sexual partners.

Then he started asking me what I had,,,pushing me ... and I finally told him ... he was suspicious! (Male, 14 years)

(2) Benefits and Costs of the Secret

According to participants, when the secret was revealed, listeners expressed their feelings by crying, hugging, with surprise and signs of immediate acceptance.

She didn't expect that I had it, she was shocked ... I think she was amazed to see that I was in college ... and had HIV. (Female, 20 years)

In terms of romantic relationships, disclosing created a greater unity for the couple, especially because partners were concerned, encouraging treatment adherence and providing psychological support.

I told her, there weren't any problems, so she's very much a friend ... (Male, 17 years)

The negative characteristics of disclosing an HIV diagnosis can be seen in some reports such as abandonment by relatives and feelings of rejection.

Oh, he did not expect that I had it, he was surprised ... Afterwards he left ... It looked like he was disgusted with me ... " (Female, 20 years)

Discussion

This study played a role in describing how adolescents living with HIV/AIDS experience the secrecy surrounding seropositivity in their daily lives. The results suggest that the secret of HIV remains restricted to the affected families, a finding also described in other countries as USA and Switzerland (Corona et al., 2009; Lima & Pedro, 2008; Michaud, Suris, Thomas, Gnehm, & Che-seaux, 2010; Paiva et al., 2011a).

Interviewees who had experience disclosing their HIV diagnosis mentioned emotional support and understanding, as well as stigma and abandonment by relatives, as described in studies at different settings (Gilbert & Walker, 2010; Siu et al., 2012; Thiengo, Oliveira, & Rodrigues, 2005; Vijayan, Benin, Wagner, Romano, & Andiman, 2009).

From this perspective, not telling is a right these teenagers have, but it is crucial to understand the meanings and function of the secret. However, most of these adolescents recognize that the right to confidentiality is not absolute. Taking the decision to disclose an HIV diagnosis involves the expectation of abandonment, a finding also described by other authors (Fernet et al., 2011; Fielden et al., 2006; Paiva et al., 2011a). The adolescents in this study perceive the risks, but at no time did they mention the possible legal consequences involved in exposing a partner to HIV, issues considered by seropositive teenagers in a Canadian study (Fernet et al., 2011). Questions of how and when to tell a sexual partner permeated the narratives of most of the participants. They must trust the other to tell them, as reported in another study (Paiva et al., 2011a), have a guarantee of the other's love, and in some cases probe their partner to find out about the rejection of the disease (Hosek et al., 2000; Paiva, Segurado, & Filipe, 2011b; Sowell, Seals, Phillips, & Julious, 2003). One limitation of the present study is the small sample and the fact that the population was followed in specialized pediatric clinics, which makes it difficult to extrapolate the results to other settings. On the other hand, it permitted the team to valorize the perspective of young people, providing spaces for reflection, encouraging and supporting their demands. They should direct the development of local guidelines and future interventions to improve care. Longitudinal studies are recommended to explore these particularities as well as the emotional risks of maintaining or revealing the secret of the diagnosis over time.

Disclosure statement

No potential conflict of interest was reported by the authors.

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