

AIDS Care: Psychological and Socio-medical Aspects of AIDS/HIV

Publication details, including instructions for authors and subscription information:

<http://www.tandfonline.com/loi/caic20>

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Published online: 23 Jul 2014.

To cite this article: Maria Letícia Santos Cruz, Francisco Inácio Bastos, Mariana Darmont, Paulo Dickstein & Simone Monteiro (2015) The “moral career” of perinatally HIV-infected children: revisiting Goffman's concept, *AIDS Care: Psychological and Socio-medical Aspects of AIDS/HIV*, 27:1, 6-9, DOI: [10.1080/09540121.2014.940270](https://doi.org/10.1080/09540121.2014.940270)

To link to this article: <http://dx.doi.org/10.1080/09540121.2014.940270>

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The “moral career” of perinatally HIV-infected children: revisiting Goffman’s concept

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(Received 29 January 2014; accepted 25 June 2014)

HIV-infected children usually live in vulnerable situations, experiencing discrimination and stigma commonly felt by other people living with HIV/AIDS. The present study aims to analyse primary socialisation of HIV-infected children and adolescents recruited from a public health service in Rio de Janeiro (Brazil) as a social process that shapes a new generation of stigmatised and vulnerable persons. Research was informed by an interactionist perspective, focusing on key aspects of HIV-infected children and adolescents life histories under the conceptual frame of Erving Goffman’s theories regarding “moral careers”. Goffman defines the making of a moral career as the process through which a person learns that she/he possesses a particular attribute, which may lead her/him to be discredited by members of the surrounding society. We have identified aspects of life histories of HIV-vertically infected children and adolescents for each aspect of “moral career” as described by Goffman, relating them to as family structure, the experience of living HIV within the family, and the position and family role of a given subject. The patterns of “moral career” proposed by Goffman in 1963 were useful in identifying components of HIV-related stigma among children and adolescents. These include gender and social disadvantages, difficulty in coping with a child with a potentially severe disease, orphanhood, abandonment, adoption and disclosure of one’s HIV serostatus. Primary socialisation of HIV-infected children and adolescents is a key piece of the complex HIV/AIDS-labelling process that could be targeted by interventions aiming to decrease stigma and marginalisation. Health care workers and stakeholders should be committed to ensuring education and guaranteeing the legal rights of this specific population, including the continuous provision of quality health care, full access to school and support to full disclosure of HIV diagnosis.

Keywords: stigma; HIV-infected children; HIV-infected adolescents; HIV vertical transmission; primary socialisation

Background

HIV-infected children are usually less discriminated against than adults. Nonetheless, if orphaned/abandoned, they are seldom adopted and accepted in schools (Foreman, Lyra, & Breinbauer, 2003). Literature on stigma affecting children with HIV/AIDS has highlighted the challenges of orphanhood and poverty, barriers to disclosure of their diagnosis, community interaction and access to health care and education (Deacon & Stephney, 2007; Foreman et al., 2003; França-Junior, Doring, & Stella, 2006; Strode & Barret-Grant, 2001).

According to Goffman (1963), stigma affects the relationship between attributes and stereotypes, fostering discrimination towards subjects/groups presenting “undesired marks”. The author describes the “moral career” of stigmatised individual as the result of what comprises the point of view of “normal” people as well as the process of learning that one possesses a discrediting attribute. The interaction of these components gives rise to four different patterns of development.

Based on the concept of “moral career”, we analysed primary socialisation (Berger & Luckman, 2002) of

HIV-infected children as a social process that may contribute to the formation of a new generation of stigmatised persons.

Methods

Profiting from an interactionist perspective (Denzin, 1989), we focused on key aspects of the life histories¹ of HIV-infected children. Data were collected in a public hospital in Rio de Janeiro, Brazil, in the context of consultations and interviews with caregivers, children and adolescents; group activities with adolescents; and meetings of a multidisciplinary team focusing on complex cases from the perspective of adherence to medications. Notes were taken on a field diary summarising difficulties faced by the team and the peculiarities of cases under management and care. Information on patients, their guardians and carers was logged into a weekly diary as part of a study about adherence to antiretroviral therapy (ART) in families living with HIV, funded by the Brazilian Ministry of Health. The diary’s contents were analysed by the authors of the present

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paper, aiming to better understand situations affecting them from a hermeneutic perspective (Denzin & Lincoln, 2011). Life trajectories' defining episodes, as highlighted by Goffman, inform the analysis. The study was approved by the hospital Institution Review Board (IRB). Patients and their caregivers have provided informed consent. Aliases replace real names.

Results

First pattern of socialisation – those with an inborn stigma who become socialised into disadvantageous situation.

This pattern illustrates the situation of HIV perinatally infected children who develop symptomatic diseases early in life and are socialised as sick persons. This was the case of a 14-year-old boy, who came to our clinic to manage a therapeutic failure. Although his immunodeficiency was moderate, he and his family were convinced that he would not reach adulthood. As he was started on new drugs, he rapidly improved, and is now 22 and has a normal life.

HIV infection became a chronic condition compatible with good health. Caregivers must be informed about the beneficial effects of ART, the importance of adherence and children's future perspectives. They must be stimulated to strive for the child's clinical recovery and to plan for their future, what should include disclosure and the social integration of the child into the family.

Second pattern of socialisation – those for whom their stigmatising condition is kept secret to them.

Disclosure of diagnosis to HIV-infected children and adolescents is a challenge worldwide (Turissini et al., 2013; Wiener, Mellins, Marhefka, & Haven, 2007) and is frequently postponed due to allegations of child's immaturity, fears that the child may tell others and feelings of guilt for having infected the child (Guerra & Seidl, 2009). In most cases, events such as schooling, drafting into the military, beginning of working careers or debut of sexual life trigger the process of (un)-planned disclosure:

Teresa was diagnosed as HIV+ when she was one and has a stepmother who did not accept disclosure that she was adopted and or HIV. When Teresa was 16, HIV disclosure occurred incidentally and the family disclosed she was adopted. Two years after disclosure, Teresa still does not accept her new identity, stopped taking her medicines, and is scared by the new reality.

In Brazil, adolescents frequently do not receive information about their diagnosis/status, although paediatric guidelines emphasise the importance of this process (Brasil, 2009; Committee on Pediatric AIDS, 1999;

Programa Estadual DST/Aids CRT DST/Aids-SP, 2008; Turissini et al., 2013; Wiener et al., 2007).

Evaluation and discussion of different forms of pre-existing stigma faced by caregivers are central in supporting them to disclose HIV diagnosis to children. Conditions such as poverty, ethnic discrimination, parents with multiple sexual partners, alcohol and illicit drug use should be discussed with caregivers.

Sometimes disclosing HIV diagnosis to a child reminds parents of their own experiences in receiving their diagnoses (Galano, De Marco, Succi, Silva, & Machado, 2012). These adults fear that children may feel like they did when they were first diagnosed. It is important to keep in mind that HIV-stigma rarely targets exclusively those living with HIV/AIDS: it overlaps and interacts with the conditions that made people vulnerable to HIV infection (Parker, 2012).

Third pattern of socialisation – those who become stigmatised late in life.

Asymptomatic children may undergo HIV testing during adolescence (Cruz et al., 2011), usually requested by a health care professional in charge of the mother's prenatal care or who is overseeing other parental health issues. Children's exams are requested without informing them about which exams they will undergo:

Laura was 12 when her mother got pregnant and knew both herself and her daughter were infected by HIV. Although scared by her diagnosis, Laura agreed to participate in group activities at the clinic. She has become engaged in a non-governmental organisation that promotes youth protagonism and empowerment.

Zelia was 12 when her stepmother became pregnant and they were both diagnosed. Zelia had no family support and at the age of 15, she started using alcohol and illegal drugs. Zelia has been absent from follow-up for two years now.

Cases facing late stigmatisation may function as "sentinel events", documenting that families have not been linked to health care system. Mothers did not receive HIV diagnosis during prenatal care or the breastfeeding period. Sometimes, diagnosis was not translated into seeking specialised care. Reasons for this delay must be explored, including previous forms of stigma that may be affecting the family (i.e., mental health problems, substance abuse and ethnic, linguistic, religious and social inequalities). These late-diagnosed youth are frequently asymptomatic and hardly believe they may need treatment. Among cases under analysis, we have observed different reactions to the (new) identity of being HIV+. Whereas Zelia did not establish bonds to institutions, Laura engaged herself in activism, in an attempt to transform her "spoiled identity" into a "project

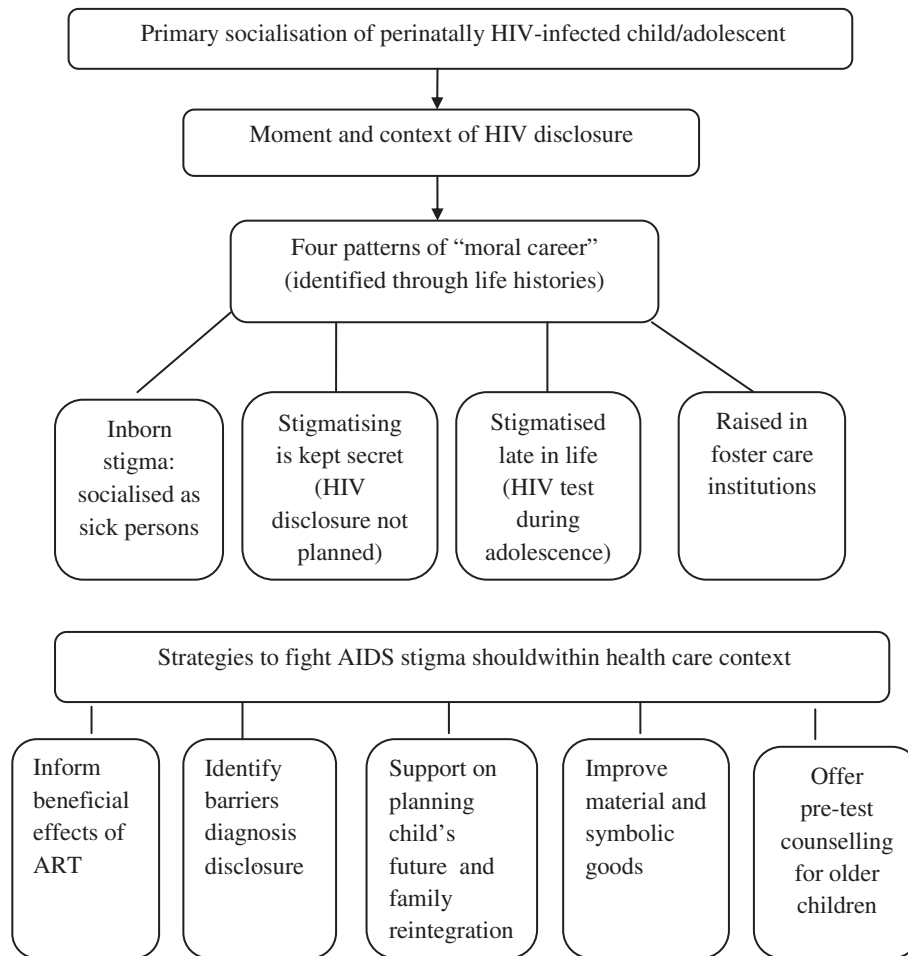


Figure 1. HIV/AIDS labelling process of perinatally HIV-infected children/adolescents.

identity” (Castells, 1999), changing her personal identity and searching for social transformation.

Fourth pattern of socialisation – those socialised in an alien community who must learn to live in the real society.

This pattern has been found among children who are raised in foster care institutions where most other children are also HIV-infected. These children are orphaned or abandoned and usually learn about their HIV condition inside the institution:

Samantha was 6 when she was admitted to a foster home. Her mother had died and her uninfected father did not accept her. Samantha lived there for 11 years and seemed happy, very close to one of the institution caregivers. At age 17, she was reintegrated into her family that still did not accept her. She suffered a severe personal crisis. Two years later, Samantha got a job and met a boyfriend. She was then fully adherent to medication, planning to raise a family of her own.

Besides the challenge of being HIV-infected, these children were abandoned by their families and have to

face other stigmatising conditions such as poverty, mental health diseases, incarceration, substance abuse or the premature death of relatives. Although in many foster homes children are raised knowing about their HIV condition and are encouraged to interact with society at large, there seem to exist obstacles in the reintegration process. As Deacon (2006) points out, stigma not only has a role in reinforcing inequalities, but it also emerges from an individual response to fear that permits those who stigmatise to feel protected from risk. Figure 1 shows the patterns of moral career for HIV-infected children.

Closing remarks

Based on the description of patterns of “moral career” proposed by Goffman, we illustrated primary socialisation of HIV-infected children by the context of HIV disclosure, its effects within social and family relations, her/his access to health care, and symbolic and material goods. To mitigate the negative impact of HIV-related stigma, interventions that could positively affect the way

these children are raised and how they learn to interact with society are needed. Strategies to fight stigma should include: information about the beneficial effects of ART and stimulating caregivers on planning on children's future; identifying barriers for diagnosis disclosure; pretest counselling for older children who needs HIV test; supporting foster care staff, youths and families during the process of family reintegration; and improved access of this population to material and symbolic goods.

Acknowledgement

We thank Amalia Bastos for the English review of this manuscript.

Note

1. Our material corresponds to abridged life histories and the respective comments of a qualified observer (the first author; Denzin, 1989, p. 189).

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