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Nurses' patterns of knowing about HIV disclosure to children

Padrões do conhecer de enfermeiras sobre revelação do HIV à criança

Patrones de conocer de los enfermeros sobre la revelación del VIH a los niños

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ABSTRACT

Objectives: to identify and analyze nurses' patterns of knowing and experiences with the preparation of families for disclosure to children living with HIV seropositivity. **Methods:** thirteen pediatric nurses from Rio de Janeiro participated in the research using the sensitive creative method. Data were treated with Orlandi's discourse analysis and Carper's patterns of knowing. **Results**: nurses' speeches revealed socioculturally constructed imaginary and ideological formations. The personal pattern of knowing, under the influence of negative media about the disease in the 1980s, generated stigma and prejudice. Empirical, esthetic, and ethical patterns were built on training and professional practice of the 1990s-2010s. They composed a context of (in)security about competence, to contribute to preparing families to disclose HIV to children. **Final Considerations:** nurses' experience demonstrates knowledge to intervene and many challenges for their practical appropriation.
Descriptors: Child; Nurses; HIV; Pediatric Nursing; Truth Disclosure.

RESUMO

Objetivos: identificar e analisar os padrões do conhecer e as experiências de enfermeiras com a preparação de familiares para a revelação à criança que (con)vive com a soropositividade pelo HIV. **Métodos:** 13 enfermeiras pediátricas do Rio de Janeiro participaram da pesquisa com o método criativo sensível. Dados foram tratados com análise de discurso de Orlandi e padrões do conhecer de Carper. **Resultados**: os discursos das enfermeiras revelaram formações imaginárias e ideológicas socioculturalmente construídas. O padrão de conhecer pessoal, sob influência da mídia negativa da doença na década de 1980, gerou estigma e preconceito. Os padrões empírico, estético e ético foram construídos nas capacitações e prática profissional das décadas de 1990-2010. Eles compuseram um contexto de (in)segurança sobre a competência, para contribuir na preparação de familiares para a revelação do HIV à criança. **Considerações Finais:** a experiência das enfermeiras demonstra conhecimentos para intervir e muitos desafios para sua apropriação prática.
Descritores: Criança; Enfermeiras e Enfermeiros; HIV; Enfermagem Pediátrica; Revelação da Verdade.

RESUMEN

Objetivos: identificar y analizar los patrones de conocer y las experiencias de enfermeros con la preparación de familiares para la revelación al niño que vive con VIH seropositivo. **Métodos:** 13 enfermeros pediátricos de Rio de Janeiro participaron de la investigación utilizando el método sensitivo creativo. Los datos fueron tratados con el análisis del discurso de Orlandi y los patrones de conocer de Carper. **Resultados:** los discursos de las enfermeras revelaron formaciones imaginarias e ideológicas construidas socioculturalmente. El patrón de conocer a las personas, bajo la influencia de los medios negativos sobre la enfermedad en la década de 1980, generó estigma y prejuicio. Los estándares empíricos, estéticos y éticos se construyeron sobre la formación y la práctica profesional desde la década de 1990 hasta la de 2010. Compusieron un contexto de (in)seguridad sobre la competencia, para contribuir a la preparación de los familiares para la revelación del VIH al niño. **Consideraciones Finales:** la experiencia de los enfermeros demuestra saberes para intervenir y muchos desafíos para su apropiación práctica.
Descriptores: Niño; Enfermeras y Enfermeros; HIV; Enfermería Pediátrica; Revelación de La Verdad.

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INTRODUCTION

Data for 2019 from the United Nations Children's Fund (UNICEF) indicate that, in the world, there are three million children and adolescents (0-18 years old) infected with HIV. Brazil is the Latin American country with the highest rate of HIV infection in this population, contributing with 39,000 new cases/year[1].Considering antiretroviral treatment availability, during pregnancy or childbirth, provided by the Unified Health System (*Sistema Único de Saúde*), the 184 cases of vertical infection represent a high number in the country[2].

The advance of antiretroviral therapy in vertical transmission prophylaxis has allowed children to survive with HIV, becoming a subgroup of children with specific and special continuous healthcare needs. This implies a reorganization in the daily routine of usual care to incorporate compliance with drug therapy, monitoring of viral load through periodic exams and a regular routine of consultations with specialists (infectious diseases specialists, pediatricians, psychologists, nurses, etc.). In this context, nurses are faced with the challenges of managing continuous medication that denounce HIV as a socially constructed stigmatizing condition. This complaint occurs because children are curious and can search for the name of these drugs on the internet and discover their HIV seropositivity status by accident, facing the risk of making public information that is stigmatizing by its social genesis. Therefore, disclosure of a sensitive condition is difficult for a child to understand that involves drug dependence (for instance). A child's family member is the key person in nurses' approach and has aroused greater interest in studies on communication and disclosure of HIV infection to school-age children[3-5].

The etymological meaning of disclosure is a noun that refers to the disclosure of a secret or confidence; therefore, it is the act of opening the veil of something that has been said before, communicated to someone before a child becomes aware of it. Disclosure, as a concept, has been appropriate to understand this process as an important milestone in children's, adolescents' and their families' lives. Stigma and prejudice complicate this disclosure, constituting a demand for care whose origin is established and maintained within the family, since it is the family's primary responsibility for disclosing it to children[6-8]. In this sense, disclosure is a phenomenon that involves actors from different social places (child, family and professional), rethinking the contribution of science of nursing in the field of diagnostic disclosure to children.

To understand the stages of science of nursing, Barbara Carper[9] stratified knowledge of nursing into four fundamental patterns of knowing: empirical, esthetic, personal and ethical.

For Carper[9], knowledge and knowing have complementary meanings, but with different aspects. From the author's perspective, there is a distinction between knowing and knowledge. The first involves the constitutive movement of having or acquiring empirical, esthetic, personal and ethical information about a given phenomenon. Knowledge, on the other hand, is built from the congregation of patterns of knowing identified in the discourses. Therefore, the identification of patterns of knowing culminates in the constitution of knowledge about the phenomenon.

The empirical pattern of knowing consists of a body of knowledge specific to science of nursing, built from the experiences of individuals and submitted to description, explanation and prediction of phenomena of interest to this scientific discipline, i.e., based on the scientific method. The esthetic pattern of knowing, whose transforming character is materialized in the expressiveness and subjectivity of the caring action, is a way of harmonizing Carper' patterns of knowing through the practical density of science of nursing. The personal pattern of knowing is socially constructed, emerging from a relationship between the self and the world, an empathic encounter in nurses' interaction that recognizes the individuals' uniqueness. It encompasses beliefs and social constructions related to the intergenerationally transmitted tradition in the cultural group, ideologically rooted in the formation of the nurses' self. The ethical pattern of knowing is given by the legal and ethical regulations of the category, and these guides for nurses' practice[9].

On the one hand, studies on HIV in childhood have been based on scientific knowledge derived from nurses' experiences with caring for people with HIV in adulthood[10-11]. On the other hand, failures in vertical transmission prophylaxis have demonstrated the need to produce knowledge centered on the experience of nurses who care for children with HIV, so that, at the opportune moment, families can disclose this condition to them. Given this context, the question is: what are the experiences and patterns of knowing acquired by nurses about HIV in childhood?

OBJECTIVES

To identify and analyze nurses' patterns of knowing and experiences with the preparation of families for disclosure to children living with HIV seropositivity.

METHODS

This article was written according to the Consolidated criteria for Reporting Qualitative research (COREQ) guidelines, which presents the methodological rigor applied in qualitative methodological procedures.

Ethical aspects

This research was approved by the Research Ethics Committee of the *Escola de Enfermagem Anna Nery* (EEAN/UFRJ) and *Instituto de Atenção São Francisco de Assis*/HESFA in line with Resolution 466/2012 of the Brazilian National Health Council (*Conselho Nacional de Saúde*) of research involving human subjects. The research that gave rise to the database was approved by the Research Ethics Committee of proposing and co-participating institutions, where family members and professionals were gathered. All participants signed the Informed Consent Form before starting the group meeting scheduled for the day.

We chose to reuse data from the bank for ethical reasons, in which we sought to preserve the research participants' integrity, not exposing them to the emotional stress of revisiting situations considered unnecessarily difficult. Data reuse suits the research approach, to answer questions that involve sensitive topics[12], such as HIV.

Methodological procedures

This is exploratory and interpretive research, with secondary analysis of the database originating from a master's dissertation entitled "*Cuidado de Advocacia no preparo de famílias de crianças com HIV/AIDS: (im)possibilidade no fazer da enfermeira*". In that research, data production occurred applying the sensitive creative method[13], a qualitative research strategy based on art, having as its structuring axis the creativity and sensitivity dynamics (CSD). For on-screen search, the CSD professional life line was chosen, with the expectation that the line art could function as a stress-minimizing metaphor, by revitalizing latent experiences about HIV in their training and professional life.

The five moments of CSD, in the sensitive creative method, are reception, individual/collective production, presentation of productions, collective analysis and thematic synthesis. In the first, the animator group (field researcher and first author) and a research assistant received participants at the door of the room, introducing them to the environment. Each person wrote on a piece of paper the name they would like to be identified during CSD, posting it in a conspicuous place. They sat in a semicircle in front of a line of string strung across the corner of the room and each person introduced themselves. In the second, the animator explained to participants how CSD would be conducted, its objectives, the time they had to fill in the empty spaces of professional life line in the elaboration of a collective artistic production, in response to the debate-generating question (DGQ): in your professional trajectory, what is your experience in preparing families to disclose HIV to children?

In the third and fourth moments, each participant presented their contribution to the professional life line while reflecting on similar and different highlights – the gradual coding of individual and collective meanings into themes and subthemes. These themes were presented to participants in the fifth stage, to deepen critical reflection, recoding and elaboration of thematic synthesis.

Each CSD meeting took place between August 2014 and February 2015 and lasted about 54 minutes. Verbal records were audio recorded using a cell phone application. Field notes recorded by the research assistant were added to the fully transcribed audios, composing the database that was submitted to the second discourse analysis, from September 2018 to January 2019.

Setting

Participants recruited from the hospital outpatient service, which is a reference in the care of children with HIV, scheduled the meetings in a place of their preference and availability. The children's hospital is located in the city of Rio de Janeiro and has a multidisciplinary team, including a nurse with a nursing consultation schedule and high-risk prenatal care.

The spaces where the meetings with participants took place were a reserved room in the clinic itself or a classroom at the *Universidade Federal do Rio de Janeiro*.

Data source

Participants were included who were nurses with care experience of at least one year and who assisted children with HIV and their families at some point in their professional life, in a reference service in the city of Rio de Janeiro and who were exposed to processes of continuing and permanent education. Participants who were on leave at the time of data collection were excluded. Participants were recruited from outpatient services in the SUS public network. A total of 13 nurses participated in one of six group meetings, organized in pairs or trios.

For CSD, the minimum number of participants is determined by the representativeness of voices in each one's discourse, the socially constructed experiences and interactions with other people that enrich these experiences. In dialogue, it is necessary to express the I-YOU and the OTHER in ME, which translates voices of other people internalized to constitute alterity[13]. In this sense, at least two people, with their polyphony of voices, are essential for developing the sensitive creative method's CSD in data production.

Fieldwork closing criteria

In the discourse analysis proposed by Orlandi[14], there are three central elements that contribute to fieldwork interruption: a) the effect of meanings constituted by participants when they use different linguistic devices (metaphor, paraphrase, interdiscourse, constitutive silence, etc.) to construct similar discursive objects; b) similarity in contexts of enunciation and unveiling of imaginary formations; and c) cohesion of discursive objects, imaginary and discursive formations to gather ideological formations.

Data analysis

The recorded empirical material was fully transcribed and manually submitted to discourse analysis, proposed by Orlandi[14], with application of Barbara Carper's knowing in nursing fields theoretical framework[9].

The discourse analysis allowed to organize, systematize and confer intelligibility to the text, applying the strategy of textual corpus desuperficialization. This material was submitted to the enunciation time marking of each participant, identification of analytical devices (paraphrase, metaphor, polyphony, etc.) and first clues of analysis that announced the discursive formation of who speaks, where it is spoken from and to which audience this speech is addressed. By proceeding in this way, the text was reordered to produce meaning, along a guiding thread that allowed the interpretation of how a discourse works from the perspective of the one who enunciates it.

Discourse alignment occurred with temporal markers used in CSD, demarcating them, from participants' academic training to current moment in which they were at the time the fieldwork was implemented. To interpret the statements, Carper's patterns of knowing in nursingframework[9] was applied in: empirical, esthetic, personal and ethical.

RESULTS

Participants were aged between 25 and 51 years, working in the public health system in Rio de Janeiro. One of them completed the undergraduate nursing course in the 1980s (N6c, 1983-1987), when the AIDS pandemic emerged. Nine participants attended the

undergraduate course in the 2000s (N2a, 1999-2002; N4b, 2004-2008; N5c, 2002-2006; N7d, 1996-2000; N8d, 2003-2007; N10e, 1993-1997; N11, 1996-2000; N12f, 2005-2009; N13f, 1999-2003), and one, in the 2010s (N9e, 2008-2011). Eight specialize in child and adolescent health nursing, three were PhDs and three were pursuing their doctoral studies. Eight were masters in nursing, and two were pursuing a master's degree.

This characterization is crucial for the conditions of discourse production on HIV in childhood and the transformations that have taken place over time. The personal, empirical, esthetic and ethical patterns of knowledge were sometimes independent, overlapping and concomitant. In this sense, the results contextualized the discourses and the production of meanings from the time when the participants lived their experiences as nursing students, beginners in nursing career until the present moment.

In the timeline of professional life, nurses' discourses intertwined the HIV theme in more than three decades at three different times. Over 30 years of the natural history of HIV infection, a knowledge modeled by nurses' personal, empirical and ethical pattern of knowing has been built, whose starting point was the epidemic emergence in the 1980s until the 2010s, when AIDS became a chronic childhood illness.

In the 1980s, public debate on AIDS flourished in Brazil. In the 1990s, there was a wide media diffusion and a period of intense social construction of knowledge in the field. In the 2000s and 2010s, there is an expressive construction of scientific knowledge about disease management and greater life expectancy of people living with HIV, culminating in its recognition as a new chronic disease.

These contexts contributed to modulate personal, empirical, esthetic and ethical knowledge, to designate nurses' knowledge. Over time, personal and scientific constructions about HIV were articulated in discursive formation, showing themselves as inseparable in the process of formation and professional practice of nurses.

The 1980s: epidemic emergence

The component of nurses' personal knowledge in the care of HIV-infected people preceded the period of professional training, in the meeting of these young women, undergraduate students, more with the common sense that circulated in the public debate of the time than in scientific literature. In the early 1980s, a nurse's discourse discloses that there was ignorance about the occurrence of this health condition among children, becoming more visible at the end of that decade.

> *I had no experience with HIV before graduation because there was no* [as a child] *at that time.* [In this time transition] *You find an extremely humble family who doesn't know what they're up against. At that time* [1989]*, AIDS gave ratings* [it was much publicly commented]*, especially in children*. (N6c)

The first experiences with HIV, in general, and not exactly in childhood, were rescued from the memory of nursing students (at the time) from the media imaginary conveyed by public opinion. The unsaid of nurses' discourse indicates that, until the end of the 1980s, there were no empirical and personal patterns of knowing. Consequently, the esthetic pattern of knowing was not applied in the first learning contacts about caring for people with HIV. Knowledge of other fields was triggered to respond to that emerging demand in society.

From the mid-1980s to the mid-1990s, scientific knowledge was insufficient to establish causal links between the virus (HIV) and the syndrome (AIDS) and which forms of treatment could increase the chances of survival. This was a period marked by many uncertainties about the future. What was seen was a rapid and devastating change in the sick person's body image, in addition to disability, late diagnosis, severity and lethality. Therefore, it was a threat to all who, in their daily lives, feared it, including to nursing students and nurses who worked at that time.

> *At college, I remember a bulletin from the Ministry* [of Health] *that HIV was transmitted by mosquitoes. A few days later, we read that it was impossible. We would read and question everything. "Does it transmit or not?" There was no information. No one knew anything. When we were in training, we used excess personal safety equipment, especially to take care of children. Everything was done to protect children.* (N6c)

In this sense, the esthetic pattern of knowing was applied, based on empirical knowledge about biosafety norms in the care of children with AIDS, and not exactly on empirical knowledge built on the disease and mode of transmission. Everything was done in favor of those hospitalized children's best interests, based on an ethical pattern of knowing.

The decade of 1990-2000: media discourse, nurses' experience and scientific knowledge

Nurses who attended undergraduate nursing courses and began their professional practice in the 1990s were involved in the social construction of knowledge and gradually internalized the few scientific advances on the HIV/AIDS health-disease process.

As part of the whole, speech production conditions of four nurses (N1a, N7d, N10e, N11e) revealed that they were immersed in a social context of publicizing AIDS images. Public celebrities (artists, singers) belonging to higher social extracts, with diverse sexual options, presented themselves as HIV-positive people. Their physical appearances were marked by extreme weight loss and disabilities; likewise, ordinary people presented themselves with the same complexions, regardless of race/color, social class or education. All this social fabric, offered to nurses, promoted an empirical knowledge capable of generating esthetic knowledge. However, initially it was guided by the imagery of death, disability, and with few common people publicly disclosing their disease, due to stigma and prejudice. In this regard, the context favors the stereotyped construction of a personal pattern of knowing focused on the lethality and physical incapacity of a person with AIDS, rather than on the potential and survival with HIV.

> *People died* [popular artists and celebrities] [...] *and other people I didn't know died. Those who showed their faces were people who looked like corpses. They were thin, they were in a wheelchair* [...] *and if they were socially or economically privileged, they had culture and education; death came for them too.* (N5c, N7d, N8d, N11e, N12f)

The intrafamily experience with AIDS contributed to form a personal pattern of knowing revealed by a study participants' saying.

> *What I associated with my experience before college was the death of my cousin with HIV. It was the 1990s, people discovered and died months later.* (N13f)

> *Before graduation, I remember a family living near my house. The mother had HIV and treated it like it was influenza, and did not know the severity* [of HIV]. (N2a)

These experiences with known people and within the family contributed to the constitution of a personal pattern of knowing, which was socially constructed and capable of generating stigma and prejudice, entering the 2000s.

> *Before college, I had prejudice. I didn't know how the pathology* [of AIDS] *worked. My understanding of the disease was the same as that of a layman. I thought it was a disease of homosexuality and promiscuity.* (N4b, N5c, N7d, N8d, N10e)

In this context, nurses' training process was based on personal patterns of knowing about the effects of AIDS on people's lives in general. It started from an empirical knowledge about biosafety, and ethical about children's best interest, which could be accessed at that time.

The decades from 1980 to 2010: discourse of science in the construction of the empirical pattern of knowing

In the training process, the personal pattern of knowing, based on the media and stereotyped discourse on HIV, assumed centrality in the acquisition of knowledge about the disease in the early years in Brazil. Students had few opportunities to learn about pediatric AIDS, particularly in relation to the disease's empirical pattern of knowing; however, the personal and ethical pattern of knowing, during internship, was incorporated through the observation of children's behavior and empathic relationship with their sadness.

In the decades of 2000 to 2010, students faced government actions to confront and control the HIV epidemic recognized internationally and disseminated by SUS. If, on the one hand, these events were marked in the imaginary formation of six nurses (N2b, N3b, N4b, N5c, N8d, N9e, N12), on the other hand, professional practices that fostered stigma, prejudice and lethality, associated with misinformation about the pathological mechanism of HIV, were dissected. Undergraduate education was insufficient to mediate empirical knowledge applicable in practice and generate esthetic knowledge.

The decades of 1980 to 2000: empirical and esthetic knowledge

Esthetic knowledge emerges with the first contacts of nurses with HIV-infected family members and the first children with AIDS. In professional practice, AZT administration, the only one available in Brazil for AIDS treatment, authentic listening implementation, comfort and support promotion marked an esthetic knowledge typical of the late 1980s. A nurse, who had the experience of caring for children with AIDS at the end of this decade, understood that comfort care and therapeutic listening took on little relevance in the treatment and cure of a disease with a high fatality rate until then.

> *There was only AZT. So, we didn't have much to do* [...] *we talked and held the hand.* (N6c)

Nurses' discursive training rescues that, in the 1990s and 2000s, there was an exaggeration in the application of biosafety norms when they played the social role of an intern in the undergraduate course clinical fields. Therefore, a sense aligned with esthetic knowing in nursing practice that paradoxically represented excessive protection of students by teachers by giving new meaning to the disease and falling ill with AIDS in childhood as painful and sad, associated with the high risk for students to become infected. Consequently, there was insufficient learning in the applicability of knowledge about care for children with AIDS.

> *I don't remember allowing us to interact with the child with HIV. My teachers found it too complicated. We dealt with adults, we never interacted with children, I think teachers wanted to protect us. It was sad to see them sick.* (N4b, N5c, N11f)

The non-rupture of prejudice, typical of personal knowledge, was a mark of esthetic knowledge that influenced care practice. Even unintentionally, there is a strain in the clinical care environment.

> *When you know that a child has HIV, you feel that way. Even without wanting to differentiate them, you differentiate. You are much more careful when they have HIV. The environment gets more tense.* (N1a, N2a)

Esthetic knowledge constructed from the implementation of nursing care for children with HIV has remained for approximately 20 years. It seems that, in the course of these years, there was a disarticulation of this empirical knowledge that broke with the imaginary formation of AIDS lethality (personal knowledge) disseminated by the media discourse.

> *When I thought about HIV, my prejudice was there. I was afraid to be close to those people, I was afraid of nursing care to the person with AIDS. When I interacted with this patient, I remember using a lot of safety equipment.* (N3b, N4b)

Lack of experience during training led them to conclude that they did not acquire enough skills and abilities to apply them in their professional lives, during the therapeutic encounter with their families. Moreover, it seems to confuse disclosure with diagnostic communication. With the exception of N6c, all other participants said they had no experience in participating in preparing families for disclosing to children

> *I did not experience the diagnosis disclosure. I must confess that I find it very complicated.* (N1a to N5c and N7d to N13f)

In nurses' professional practice, esthetic knowledge about the disclosure occurred at the family member demand. When she was triggered by a family member, she became aware that the

ability of empirical knowing in nursing could meet this demand for care. The nurse-child-family member bond was a facilitator to do nursing in that context. However, work overload was an obstacle to proceeding with the construction of esthetic knowledge about the process of preparing families for disclosing children's seropositive condition.

> *I remember a mother asked us to be with her when she told her son. It was interesting and I think nurses have the knowledge for this, but they require a bond with the family and we are not always able to build it during the shift, because there are many things to do.* (N6c)

In this sense, four nurses acquire esthetic knowledge in therapeutic management for antiretroviral therapy treatment.

> *I need to take care of other demands* [from the child] *how to teach them how to swallow the medication or guide parents about consultations and treatment compliance.* (N6c, N8d, N9e, N12f)

Ethical knowledge about disclosing HIV in childhood acquired meaning in the discourse of nurses with the recognition of children's right to know about their serological condition. Similarly, the advantages to increase children's support to the therapeutic process were perceived. Because, after doing so, there is greater fluidity and freedom in communication during the therapeutic encounter in the health service. This dialogue favors individual orientations and children's health education to make it autonomous in their care.

> *I see difference when they know* [the diagnosis] *because I can talk to them about. They ask questions, they want to know about the medication, the tests* [...] *girls ask about menstruation, how to date, if they can have children* [...] *things as such.*(N5c)

In the speech of two nurses, ethical knowledge emerges in the empathic movement of the therapeutic relationship with children, having as an imperative children's right to know about their health condition. Therefore, the spaces of health institutions (hospital or primary) have the responsibility to respect children' rights.

> *I did not participate directly, but it is important that the child knows their diagnosis. It is your right and it is our job to ensure that they are respected in health spaces.* (N5c, N8d)

However, insecurity and discomfort were obstacles to the application of knowledge in favor of children's best interest. This trend shows that empirical and ethical knowledge has been based on biomedical ideology, internalized by nurses, especially in the field of clinical care.

> *I am not comfortable talking about the subject* [disclosure of HIV to children] *with families.* (N6c, N8d, N9e, N11, N12f)

> [...] *difficult to know what I can say or not; Isn't it the doctor's job?* (N6c, N8d, N9e, N11, N12f)

In this sense, discursive formation reveals that esthetic knowledge emerging from professional practice, related to diagnostic communication, was developed as a uniprofessional and medical-centered action.

DISCUSSION

The personal, empirical, esthetic and ethical patterns of knowing about HIV in childhood acquired visibility in the discursive formation of nurses participating in the research as a social and scientific construction. This contributed to provide nurses with an ontological view of their professional competence to participate in preparing families for disclosure of HIV-positive condition to children. Over almost three decades, the media, social and personal contexts of their lives influenced the formative and professional process; however, stereotyped historical-social constructions about HIV in childhood were also part of their imaginary formations.

The second decade of 1980 was marked by media dissemination of the first cases of AIDS in childhood, both in the world and Brazilian press. Initially, the syndrome manifestations were emphasized, a historical-discursive construction centered on the disease and not on the person, be it an adult or a child.

Nurses' discursive formations on preparing families to disclose HIV to HIV-positive children revealed socioculturally constructed imaginary and ideological formations. The unsaid, a new meaning by nurses revealed that, as a student, they did not maintain contact with esthetic knowledge, which led them to have insufficient knowledge to care for a child with HIV. Consequently, previous inexperience constituted an imaginary formation that preparing families for disclosing children's seropositive condition was not within their competence. However, the ethical pattern of knowing emerges with the contemporaneity constituted in practice and knowledge acquired in the 2010s, when the scientific and legal contexts provided the recognition of the importance of disclosure to children.

In 1983, those participants who were still taking their undergraduate nursing course witnessed the notification of the first case of AIDS in childhood. Despite this, it is a time in which a leading Brazilian newspaper had published an article entitled "the gay plague", to describe AIDS as the worst disease of all time. The term "plague" is related to characteristics of fatality and body transformation, but, in AIDS, it was still associated with the shame that blamed individuals for their health condition[15-16].

At the beginning of the AIDS epidemic in the country, nurses came into contact with this type of media language, which contributed to the construction of a stereotype that remained a constitutive part of their personal pattern of knowing. Even though HIV stigma and prejudice were manifested subtly and unconsciously, with expressions of fear, "there is nothing more to do", indicating that there was interference in the quality of care provided. Among the manifestations, looks with significant nuances, attitudes driven by fear, inconvenient questions, uncomfortable conversations and even refusal to assume a certain user stand out[17-18].

The fact is that, in the beginning, there was little creditable knowledge about the disease and little learning experience in the undergraduate course. Therefore, empirical, esthetic and ethical patterns were constructed in training and professional practice in the decades of 1990-2010. These patterns coexisted, either independent, overlapping or concomitant, composing a context that generates (in)security about their competence to contribute to preparing families during the process of HIV disclosure to HIV-positive children.

In this regard, the knowledge acquired at the time (1980-1990) about HIV, on the one hand, produced prejudices, distortions about the mode of transmission and excesses of application of biosafety standards. On the other hand, they also contributed to the constitution of an ethical body of knowing by valuing pediatric patients' interests as a guide of the way of caring.

There is a tension, which resides in the type of care remodeled in the hospitalization of children with HIV/AIDS, by providing a differentiated care environment due to excessive use of biosafety norms, even without realizing that there was prejudice. In this sense, there is an articulation of personal, empirical and esthetic patterns of knowing with absence of ethical knowledge, since the latter is marked by the empathic movement to clients.

Language is an important ally in coping with prejudice and structural stigma in HIV/AIDS[19]. It is through words those social meanings are deconstructed and reconstructed, and the health team nurse can act in preparing families to disclose HIV to HIV-positive children. However, centralization of care in procedures is one of the challenges to implementing an approach that values authentic listening and early guidance. Authentic listening favors communication with the family to know its history and understand how it experiences the health condition. On the other hand, advocacy care involves nurses' role as an advocate for children's right to participate in their healthcare, which begins with access to information about their HIV status[8,20-21].

Nurses' personal pattern of knowing about HIV in childhood and how they understood nursing care influenced the way to approach the issue with preparing families to disclose children's HIV to them. The term HIV is used, since the name AIDS is associated with a disease loaded with stigma and prejudice; this linguistic condition reinforces the founding silence, contributing to stigma and prejudice. Despite recognizing children's right to access information about their health, imaginary formations centered on the biomedical paradigm still leave nurses insecure about their legal competence in the face of this phenomenon.

On the other hand, research shows that the family indicates nurses as competent professionals who participate in the process of preparing them to talk to children about their HIV[8,23-24]. Disclosing HIV in childhood favors compliance with antiretroviral therapy, since awareness of their health condition enables dialogue with children, helping to understand the importance of therapy and participation in self-care[7,22-23].

As the science of HIV/AIS was under construction, in the first decade of the syndrome emergence, the dominant ideological formation at the time reveals that personal knowing guided care practices, due to the absence of sustainable empirical knowledge. They recognized these constructions themselves and considered themselves lay before starting their professional practice.

In the current literature, advocacy care emerges as a possibility of nurses' work in preparing families to disclose children's HIV to them. Advocacy care practice takes place from the recognition of children as moral agents with the right to know their health condition and participate in their care. This type of nursing practice favors the preparation of families to talk to children about HIV in the face of emergence of questions from children who have the ability to understand health information. Advocacy care, exercised by nurses, works in a perspective shared with the family. It is considered that these have expertise in the care of their children and that working together can promote empowerment and autonomy of the family to deal with a sensitive issue such as HIV/AIDS[8].

Study limitations

The research development in the public health sector of Rio de Janeiro stands out as a study limitation, requiring research with this design in other scenarios and contexts.

Contributions to nursing, health, and public policies

It is necessary to recognize that disclosing to children about their serological condition brings advantages to the therapeutic process, as it allows greater fluidity and freedom in the communication that takes place in the therapeutic encounter between nurses, children and their families. It is a child's right to know what is happening to their body and their experience of illness. Thus, the development of more autonomy in self-care is promoted in the condition and treatment management. The nurse-child-family member bond can be a facilitator for nursing in that context.

The findings reinforce the need to apply authentic listening and early guidance in preparing families and post-disclosure follow-up. In doing so, advocacy care will be promoted throughout the process and not only at the time of reporting the HIV-positive diagnosis. Nursing interventions are based on scientific (empirical pattern of knowing), esthetic and ethical knowledge of children's right to participate in decisions about their health as one of the perspectives of clinical care. In this sense, nurses' legal and ethical responsibility, proper to the ethical pattern of knowing, guides nurses' esthetic pattern in the care of children and their families.

FINAL CONSIDERATIONS

Over the decades, nurses' patterns of knowing about disclosure to children living with HIV seropositivity were constituted from the conditions of production of their speeches, with the phenomenon of disclosure being a contemporary demand. Therefore, non-existent in the 1980s, 1990s and 2000s.

The meaning of HIV in childhood as the cause of an unknown and lethal disease, signified in the past, does not coincide with current times, which has come to be considered as a chronic condition. However, the imaginary formations built with the natural history of AIDS contributed to nurses not recognizing themselves as part of the interdisciplinary team in preparing families for HIV disclosure to children. Nurses' experiences demonstrate that they have scientific knowledge to implement the approach to families of children as a form of care; however, stigma and prejudice constitute challenges for them to appropriate this practice. The four types of patterns of knowing are manifested in a punctual way, and the personal pattern is ideologically predominant, revealing that stigma and prejudice, even being structural, are not monolithic.

Nurses constituted intersections between the patterns of knowing personal and empirical with esthetic and ethical knowledge. The personal pattern of knowing disclosed the media discourse of

AIDS as a disease that produces stigma and prejudice with little reliable information at the time of the pandemic emergence. This pattern transitioned to the empirical pattern of knowing only with the insertion in professional training during the undergraduate course, but in a timid and sometimes controversial, paradoxical or excessive way. The esthetic pattern of knowing was marked by recognizing children's right to know about their health condition. The ethical aspect emerged in the recognition of children's rights and the legal responsibility of nurses in the process of preparing families for disclosure.

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