Disclosure of AIDS diagnosis to children from the family members' perspective

REVELAÇÃO DO DIAGNÓSTICO DE AIDS À CRIANÇA NA COMPREENSÃO DE FAMILIARES

REVELACIÓN DEL DIAGNÓSTICO DE AIDS AL NIÑO EN LA COMPRENSIÓN DE FAMILIARES

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ABSTRACT

This phenomenological study aimed at understanding how the care-giving family sees the disclosure of the AIDS diagnosis to the infected child, founded on the philosophy of Martin Buber. This study was performed at a teaching hospital in Porto Alegre, with seven family members of children with AIDS. Data collection was performed through phenomenological interviews and interpreted guided by hermeneutics. The dialogues for disclosing of the diagnosis to YOU child with AIDS show that this situation occurs in the experience lived by those caregivers and interferes in their existentiality, as it when they establish relationships with the other, in the world. The disclosing of the AIDS diagnosis to the child is a complex phenomenon that generates dialogues related to the everyday situations shared by the caregivers and the children. Further studies are needed on this theme that is constantly increasing in health services, which would take into consideration the dynamicity and singularity of the rumors taken by this epidemics in the Brazilian context.

DESCRIPTORS

Acquired Immunodeficiency Syndrome
Child
Diagnosis, clinical
Family
Caregivers

RESUMO

Pesquisa fenomenológica que buscou compreender como a familiar cuidadora percebe a revelação do diagnóstico de aids à criança, fundamentado na filosofia de Martin Buber. Realizou-se em um hospital-escola de Porto Alegre com sete familiares de crianças com aids. A coleta das informações ocorreu por meio da entrevista fenomenológica e, para a interpretação, recorreu-se à hermenêutica. Os *diálogos para a revelação do diagnóstico ao TU criança com aids* demonstram que esta situação está presente no vivido por estas cuidadoras e interfere em sua existencialidade, ao estabelecer relações com o outro, no mundo. A revelação do diagnóstico de aids à criança é um fenômeno complexo e que gera diálogos relacionados às situações cotidianas compartilhadas pelas cuidadoras e crianças. Acredita-se na necessidade de outras pesquisas sobre esta temática, cada vez mais emergente nos serviços de saúde, e que considerem a dinamicidade e singularidade dos rumos tomados por esta epidemia no cenário brasileiro.

DESCRITORES

Síndrome da Imunodeficiência Adquirida
Criança
Diagnóstico clínico
Família
Cuidadores

RESUMEN

Investigación fenomenológica que buscó entender cómo el familiar cuidador percibe la revelación del diagnóstico de AIDS al niño, fundamentado en la filosofía de Martin Buber. Se realizó en hospital escuela de Porto Alegre (RG-BR) con siete familiares de niños con AIDS. Se recolectó información mediante entrevista fenomenológica, interpretada por hermenéutica. Los diálogos para la revelación del diagnóstico al TU niño con AIDS demostraron que esta situación está presente vivencialmente en las cuidadoras e interfiere en su existencialidad, estableciendo relaciones con el otro, en el mundo. La revelación del diagnóstico de AIDS al niño es un fenómeno complejo y que genera diálogos relacionados con las situaciones cotidianas compartidas por cuidadoras y niños. Se coincide en la necesidad de investigaciones enfocadas a cuidadoras y niños. Se cree en la necesidad de otras investigaciones sobre esta temática que consideren la dinámica y singularidad de los rumbos de esta epidemia en Brasil.

DESCRIPTORES

Síndrome de Inmunodeficiencia Adquirida
Niño
Diagnóstico clínico
Familia
Cuidadores

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INTRODUCTION

Disclosing a diagnosis to a child, regardless of the disease, is an issue long discussed in the health services and remains a concern in diverse branches of knowledge[1]. The following are typical issues among those that permeate the disclosure of a diagnosis to a child: who should disclose the diagnosis, how it should be disclosed, what should be said, when is the best time to disclose it, who should know the diagnosis, what family and social support will the child have after disclosure, among others[1-3].

Hence we perceive that disclosing a diagnosis to a child is a phenomenon permeated by different nuances since it involves decisions the family and the health team have to make. The child has both possibilities and limitations in understanding the diagnosis, in addition to aspects peculiar to the experience. The challenge is even greater when the diagnosis involves the Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome (HIV/AIDS) given the prejudice and stigma still linked to the epidemic[4], especially in relation to pediatric AIDS.

We argue that the disclosure of the AIDS diagnosis is another phenomenon included in the context of the chronicity[5] of this epidemic and requires responses appropriate to its complexity because it involves aspects ranging from cognitive evaluations to the fact that the family and the health team have to disclose the diagnosis to its peculiarity given the different family relations, life conditions, involvement of health services and others. Even given all these concerns, there are few Brazilian studies addressing this theme, especially when the serological status to be disclosed is related to children.

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OBJECTIVE

This study aims to understand how family caregivers perceive the disclosure of the diagnosis of AIDS to children based on the philosophy of Martin Buber. The unit of meaning *dialogues to disclose the diagnosis to a child as-THOU with AIDS* was found, which shows that this phenomenon is experienced by caregivers and appears in their experience, sometimes facilitating, sometimes hindering the establishment of relations with another in the world.

PHILOSOPHICAL FRAMEWORK

The work of Martin Buber holds as central concepts *relationship* and *dialogue*, from which the human being comes to exist and manifest him/herself in the world[6-8]. These two constructs are mutually interconnected and interdependent, even permitting the development of other concepts such as *presence*, *relationship*, *daily situation* and *community*, also important to understand its complex philosophical thinking, which, generally speaking, proposes to give an opportunity to reflect upon reflection and incites one to make a commitment to such an experience.

The philosopher understands that the world is multifaceted for the human being, who can assume one of the possibilities of existence: one may enter in an authentic manner into the relationship established by the word-principle I-THOU or experience the objectifying relationship of the word-principle I-IT. These configure attitudes that are essential to the human being, while the first is a form of presentification, the meeting of two beings who are open and available to update themselves existentially, reciprocally and mutually, while the second is an experience, the use of I over something, which is essential to construct and develop knowledge from science that rules the world.

Therefore, one has to take into account that these attitudes, essential to human beings, are possibilities for I to authentically and genuinely understand and perceive both THOU and IT and later understand and perceive him/herself as a being-in-the-world. Hence, the existence of the human beings is in intrinsic harmony with the continuous succeeding of these words-principle because when one becomes a way-of-being, the other becomes latent, in a dynamic and exclusive movement, though closely connected[6].

The dialogic relationship is understood as a possibility of existence of the being in the world since it is the word that introduces the human being in the world when this being is with him/herself and with another, keeping the otherness of both even during the presentification of the relationship I-THOU. The Buberian word is uttered in the search for an existential dialogue with another and is deeply committed with what is experienced by the being and is an active presence of I with THOU[6-7].

In nursing, the relational-dialogic philosophy of Martin Buber was first used to support and develop the Humanistic Nursing Theory of Paterson and Zderad[9], which considers professional practice to be a live dialogue that occurs face-to-face between the being who is being cared for and the being who cares for, while caring is the response to a help request. The Buberian framework has enabled reflection, questioning, and proposals of contemporary studies developed by nursing[10-11], since in the world of care *the existentialist nature of the inter-human I-thou relationship that is concretized in the intersubjective dialogue* as well as *in the subject-object relation manifested in the binomial I-it*[12] so that knowledge is produced.

From this perspective, this study considers that the *I* will be the family caregiver of the child with AIDS, all

women, biological mothers, foster mothers or maternal grandmothers. *THOU* will be the child with AIDS being cared for and the dialogue is what enables one to turn-to-another as a way to reveal oneself to the world, toward the domain of common existence. The dialogic meeting enables the inter-human relation to happen, in which responsibility is an essential condition of who asks and who answers, based on a free decision of being-with another. Therefore, the dialogue is no longer a concept constructed in the abstract sphere of ideas and becomes constituted in what is experienced and describes human experiences[7].

Hence, we depart from the understanding that the phenomenon of disclosing the AIDS diagnosis occurs amid the presentification of the relationship established between the family caregiver I and the child with AIDS THOU and is permeated by the dialogic word. Therefore, it is believed that the Buberian framework, when applied to the context of the HIV/AIDS epidemic can contribute to this specific field of knowledge, especially when one considers issues related to the disclosure of the AIDS diagnosis to a child, and all the aspects that facilitate and/or hinder its concretization.

METHOD

This is a qualitative study with phenomenological approach where the researcher considers a phenomenon as essential, aiming to understand it in its totality and complexity based on the experiences of being-in-the-world and being-in-the-world-with-another in a given shared time and space. A phenomenological study enables the researcher to become familiar with the experiences of the studied individual in his/her world aiming to minimize prejudices and preconceptions and enable the phenomenon to be revealed as it is[13].

This study was carried out at the Pediatric Outpatient Clinic of the Pediatric Service of a university hospital in Porto Alegre, RS, Brazil, which is a large public and federal facility that provides care, and also develops teaching, research and extension activities. The interviewees were intentionally selected in the service, taking into account their openness to be-with, their interest and availability to participate in the study. They were seven family caregivers of children with AIDS, of which four were the biological mothers, one foster mother, and two maternal grandmothers.

Data collection was carried out during September and October 2006 through a phenomenological interview[14], which allows one to reveal the original report, from the genuine language of the interviewee based on his/her experiences and understanding of the phenomena of his/her world. Because phenomenology seeks the essence of human experiences, the reports reproduced here kept the authentic way-of-being and talking of the interviewees, that is, all the tics and errors in spoken language were kept because they constitute the genuine way these beings manifest in the world, with themselves and with-another. Aiming to preserve the confidentiality of the participants' identities, the reports are identified as F1 to F7.

Hermeneutic philosophy[15] was used in the interpretation of information, which allowed uncovering the primary meaning of the reports so as to bring to light what was hidden, veiled in between the lines. From this perspective, it is necessary to know and enter the world of life of the family caregiver based on the meeting experienced and dialogued in the phenomenological interview, focusing not only on the observable and verbalized, but seeking to achieve what is undercovered in this existential experience. Ethical issues were complied with as provided by the Resolution 196/96 of the National Council of Health[16] and approved by the Research Ethics Committee at the institution (protocol nº 06-122).

RESULTS AND DISCUSSION

The dialogic understandings established in the relationship family caregiver I and the-child-with-AIDS-THOU and which exist in the meeting *between* them, enable or not, the disclosure of the AIDS diagnosis, are then presented. The dialogic relation that emerges from the description of the family caregivers enable us to signify this existential phenomenon - disclosing the diagnosis - as a moment that involves the being-with-another in the totality of his/her being, and also perceive there are facilities and difficulties that are signified in the beings' experiences.

It is also worth noting that the dialogue in Buberian thinking[6] goes beyond a mere psychological mechanism or means of communication, while the presence of elements such as listening and talking, co-responsibility and being-with-another is essential. The dialogue therefore is responsibility of I with THOU and *vice-versa* and though it does belong to any one of them, it is kept 'between' them. The authentic dialogue will only occur between I and THOU at the moment in which each sees and perceives the other in her/his otherness as s/he essentially is, as s/he genuinely is presented as being-in-the-world.

The dialogic relation established between the family caregiver I and the-child-with-AIDS-THOU reveals itself to be a phenomenon of presence in the world with-another and has a special place in the existentiality of both. The many dialogues that are presented to the experience of these beings are highlighted when the theme that emanates from this relation I-THOU is the disclosure of the AIDS diagnosis to the child as the following report shows:

> Because the child asks you and you have to, you can't gloss over too much, you have to explain why, 'cause the longer you take, it's worse because if you fool the child you get to a point when you don't manage to tell the truth because you've fooled her for too long, you don't know even know what to do, then you go and tell the truth and disappoint them. So, I guess it's better you slowly tell them, you know, you tell the truth in a childish way, then in a way more, in a

> More adult way […] I always tell, explain everything to him […] I let him know the real thing, you know, I don't, I don't gloss over anything. I say it like, with a childish way, but I tell the reality, you know! I don't gloss over anything to him, so that tomorrow, later he doesn't get shocked, he's going to be a child who doesn't, he'll only know the real name. He knows he is HIV positive! (F2).

This report shows that the caregiver establishes with the child with AIDS a conscious and responsible dialogue, and is concerned not with the current point in time of the I-THOU relationship but also and especially with future issues that will mark the way the child will signify the information received in the past and that he will project in his existentiality. Hence, one has to consider that a dialogue cannot be imposed on anyone, since answering is not a duty, it is rather power[9]. This is because the human being is a dia-logal and dia-personal being, that is, s/he uses the dialogue to enter in a face-to-face relationship with another. In this context, the dialogue is something that occurs *between* two beings in the reciprocity of the existential meeting and, therefore, revealing to another and revealing to another phenomena shared in the I-THOU relation is a possibility.

We also perceive along the report that the family caregiver signifies the disclosure of the AIDS diagnosis to the child as a special moment, which needs to be focused on the needs of the other who presents him/herself to the dialogical relationship. Hence, answering questions asked by the child with responsibility is to offer answers appropriate to the abilities and limitations inherent to this being; it is important to clarify his/her doubts and concerns.

The family caregiver I explains that she should not gloss over the disclosure of the AIDS diagnosis so that the child is not disappointed and suffer some kind of a *shock* in the future with the disclosure of the real name of the disease that is already part of his/her experience. The report also shows that establishing a dialogue in such a way in which the diagnosis is slowly and gradually revealed is essential, first in a *childish way* and later in a *more adult way*.

This concern manifested by the family caregiver can be also understood as responsibility to answer to the word evoked by the act of asking and which is manifested when there is intimacy in the inter-human meeting[6-7]. The family caregiver I presentifies the child THOU as a being who meets with another in the world in his/her totality, glimpsing the essence of her/his way of being and showing her/himself to another. This dialogic relation is also still permeated by other elements that are part of these beings' experiences as the following reports show:

> They even know they have the problem, they know because they listen, you know, and they ask because they take medication and things, you know, and we explain. Only that for them, you know, for them who are young, it's kind of difficult, you know, I guess they'll start to understand when they are a little older, you know. But it's not because of it I don't tell, I don't explain, I don't warn (F3).

> She knows that she has a disease, that she has to take medication. We explain, you know, but she doesn't know she has the virus. We tell her she has to take medication, that her dad died because of this same problem she has, we tell her everything, but she doesn't ask much, she is like…she keeps things to herself… (silence) (F7).

We consider that the disclosure of the diagnosis comes from a need the child has, that she wants to know, which is in agreement with the findings of other studies[1,17]. When the child asks the question related to issues present in her/his life, the child enters a dialogic relation with the family caregiver I who is compelled to answer the existential appeal presented face-to-face in the inter-human meeting responsibly. It is the act of asking and the act of answering that establishes the dialogue that will enable disclosing the AIDS diagnosis to the child. The dialogue therefore corresponds to an explanatory form of the phenomenon, assuming there is reciprocity between the beings[7, 18].

The reports allow us to understand that the administration of the anti-retroviral treatment is an important issue present in the experiences of the child with AIDS as evidenced by another study[19]. It is the desire to know about the need to take medication that leads the child to ask questions. Amid these questions, the family caregiver answers the child according to his/her comprehension abilities. It is, however, believed that providing a full explanation is not possible given the child's tender age.

In this context, the dialogues established during the disclosure of the child's diagnosis, even if the name of the virus and/or disease is not explicit, are closely related to the need to use anti-retroviral and also with questions that permeate the dying process and death. The family caregiver I considers the dialogic relation established between I-THOU is important because it is necessary to tell, explain, warn, however the serological status or the disease are expressed as something that is part of what is experienced.

It is understood that the fact the family caregiver does not explicitly say the name of the disease and/or serological status that is related to the disclosed diagnosis does not invalidate or void the possibility of entering in a dialogic relation with the-child-with-AIDS-THOU since this attitude shows the responsibility present in the I-THOU relation. The responsibility resides in the awareness of the need to keep the bonds existent *between* them, confirming the maintenance of a meeting with-another based on an active presence, dedication and love, essential for this relation to occur[6].

The family caregiver also reveals the existence of some facilities in this act of answering to the question that emerges in this dialogic relation, which can be observed in the following report:

> I've already disclosed it to her…(silence) […] so I explained what she can do and what she can't do, you know, and I thought she'd rebel, it was exactly six months ago, I guess, five, when she came here (hospital). Then I said to (name

> of the physician), but no, she treated herself normally, she didn't have that thing of looking to a friend, look to another friend and say: *oh, I'm different*. No, you know, she only knows that she has to take care, that she has to take medication […] we are very kind, are very warm with her, I'm always talking to her about everything and about it, you know, and she acknowledges it. How can I say, I don't know what's inside her heart, you know, but apparently, she didn't have those sudden changes, had no aggression or anything, you know, she's normal. Then she said that she'd rather know through me than through someone else (F5).

Facilities manifested in the dialogues are uncovered by the family caregiver as a moment that results from a process in which the child is warmly cared for and through everyday conversation, which allows the child to feel *normal* not causing aggressiveness or *sudden changes* and which requires the responsibility to self-care, such as in adhering to the anti-retroviral treatment. The family caregiver understands that she kept her way of being-in-the-world, showing herself to another and being perceived by this other being in the same way as she was previously perceived, which somehow is understood as a facility at the moment of disclosing the AIDS diagnosis to the child.

The dialogic relationship *between* the family caregiver I and the-child-with-AIDS-THOU occurs in the existential meeting in which both are present in their totality and in which their experiences are shared in an authentic and genuine manner so as to allow the being of essence to show her/himself to another and manifest her/himself in the world[6, 18].

The reports reveal that a concern emerges from the act of disclosing the diagnosis of AIDS to the child that is manifested in the existentiality of the family caregiver when being-with-another, unveiled by the belief that the child *acknowledged* the condition s/he is going to live with though what goes *in her heart is not known*. The family caregiver I becomes concerned with aspects that pervade the conditions manifested but not verbalized by the child, with issues that she – the family caregiver – also experienced when she learned about her diagnosis of AIDS.

The disclosure of the diagnosis can also be facilitated when the family caregiver is the mediator of the information provided in the dialogue. It is inferred that the child prefers to be informed about the diagnosis by her family caregiver rather than by someone else, a fact also revealed in another study[17]. This preference may be explained by a daily intimacy established between the family caregiver and the child with aids in the I-THOU relationship, which includes intimacy, responsibility, love and reciprocity in the existential face-to-face that configures the dialogic relation[6-7].

However, the family caregiver manifests this as a moment when there are difficulties shared in the experiences with the other person, in the world. The following reports exemplify this occurrence:

> so, it was difficult in the beginning. One day my daughter was like, so, we're having breakfast and she asked me: *mother, why do you take so many medicines?* Then I told her, it, it was difficult to tell her, because you have to be prepared, you know, and I, I wasn't at the time, so I said it: *your mother is HIV positive* No! (F1).

> At the beginning my husband thought it wasn't a good time to tell because I couldn't explain it very well to him…[silence] (F2).

The reports show that there is a need on the part of the family caregiver to feel *prepared* to enter into a dialogic relationship with the child and disclose the diagnosis of AIDS. This lack of preparation is signified as a difficulty existentially experienced when being-with-the-other who requires an answer. The family caregiver reports that the questions about the diagnosis are motivated mainly due to the use of anti-retroviral drugs by the family caregiver herself, of how it is perceived and signified by the child, which is also evidenced in other studies[1-2].

Another difficulty is faced in addition to the need to feel prepared to disclose the diagnosis of AIDS, which is related to whether the other family members acknowledge the disease. The serological status of the HIV carrier is part of the world of this family and, hence, the acknowledgment or lack of it by these other members interferes in the decision the caregivers make. There seems to be a fear of exposing the history of this family, that they believe the child is not yet prepared to keep this secret; the child's own maturity is questioned and often denied in order to keep this pact of silence[4,20].

As the reports are uncovered we perceive there is a distance between the caregiver and the health team since the health team could have provided the guidance the family caregiver needed when she experienced existential situations that required the need to authentically dialogue with the child with AIDS to disclose the diagnosis. It is amid these perceptions and significations of being launched into the world with little professional help that the caregiver sees herself as the one responsible for the dialogue that will lead to the disclosure of the diagnosis of AIDS to the child; the family caregiver I describes her existentiality in the face-to-face of the dia-personal relation.

CONCLUSION

From the understanding about what it is like to be a relative of a child with AIDS and amid the established dialogic relationship emerges the phenomenon disclosing the diagnosis as a complex situation that generates existential dialogues related to daily situations shared by the caregivers and their children in the world. From the reports of family caregivers some dialogic paths that lead to the disclosure of the diagnosis of AIDS to the child were uncovered as well as perceptions that indicate there are facilities and difficulties experienced by the family caregiver I who lives with HIV.

The reports enabled us to perceive that disclosing the diagnosis of AIDS to the child is part of the experience of family members and is signified as a phenomenon that generates concern. Issues of when to disclose, how to disclose and what

is the level of consciousness and maturity required from the child appeared as persistent questions, which are present in the dialogic relationship established between the caregiver and the child. Other concerns also emerged such as those related to the importance of not lying to or fooling the child in relation to the diagnosis, providing information consistent with his/her doubts, knowledge and development of being-in-the-world, as well as related to the lack of preparation experienced by the family members to deal with the situation.

Therefore, the existential situation of whether or not to disclose the diagnosis of AIDS to the child is part of the existentiality of the family caregiver and permeates the family's experience interfering in the I-THOU relationship. The dialogues that lead to the disclosure of the diagnosis are perceived as facilitators. Disclosing the diagnosis enables the child to better adhere to the anti-retroviral treatment and self-care. However, it is also perceived as a difficult situation because the child with AIDS may not be prepared to know about her/his disease and/or serological status as well as the fact that once s/he learns about the diagnosis, she might reveal it to other people and break the family's pact of silence and expose them all to prejudice and discrimination.

Finally, further research addressing this subject that is increasingly emergent in health facilities and services is needed in order to encompass its complexity, dynamics, and the singularity of the direction of this epidemic in the Brazilian context. It is important to investigate this subject in the light of different theoretical-methodological references to promote a connection between them and permit conclusions to be drawn from all the interfaces existent among them and enable the improvement of health practices and the development of ethical, scientific, aesthetical and humanistic care focused on the needs and potential of people who live with HIV/AIDS, especially children.

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