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Education in health in the waiting room: care and actions to the child who lives with HIV/aids

Educação em saúde na sala de espera: cuidados e ações à criança que vive com HIV/aids

Educación en salud en la sala de espera: atención y acciones al niño con VIH/sida

Paula Manoela Batista Poletto[1]
Maria da Graça Corso da Motta[2]

1. Fundação de Proteção Especial do Rio Grande do Sul. Porto Alegre, RS - Brazil.
2. Universidade Federal do Rio Grande do Sul. Porto Alegre, RS - Brazil.

Abstract

Objective: Learning under the point of view of the child who lives with HIV/AIDS the care and actions of health education that may be developed in the waiting room. **Methods:** It is a descriptive and exploratory research with qualitative approach carried out in a healthcare service specialized in DST/AIDS in the city of Porto Alegre/RS. The participants comprised children between seven and twelve years old attended in this healthcare service and their family members/caretakers. The collection of information followed the Creative and Sensible Method. **Results:** The thematic analysis provided the themes for the health education activities. This article discussed the following themes: waiting room, self-care, health in the school, and health representations. **Conclusions:** The waiting room configures a space that may provide a moment of pleasant and productive waiting time by introducing activities that develop health education with emphasis on the ludic factor.

Keywords: Child; Pediatric nursing; HIV.

Resumo

Objetivo: Conhecer, sob a ótica da criança que vive com HIV/aids, os cuidados e as ações de educação em saúde que podem ser desenvolvidos na sala de espera. **Métodos:** Pesquisa descritiva-exploratória, com abordagem qualitativa, realizada em ambulatório de atendimento especializado em DST/aids na cidade de Porto Alegre/RS. Os participantes foram crianças atendidas nesse serviço de saúde, entre sete e 12 anos de idade, e seus familiares/cuidadores. Para a coleta das informações utilizou-se o Método Criativo e Sensível. **Resultados:** A partir da análise temática emergiram os temas para as atividades de educação em saúde, neste artigo foram abordados os seguintes temas: sala de espera, autocuidado, saúde na escola e representações de saúde. **Conclusões:** A sala de espera configura-se um espaço que pode proporcionar momento de espera aprazível e produtivo com a inserção de atividades para desenvolver educação em saúde, com ênfase no lúdico.

Palavras-chave: Criança; Enfermagem pediátrica; HIV.

Resumen

Objetivo: Conocer, bajo el punto de vista del niño que vive con HIV/SIDA, los cuidados y las acciones de educación en salud que pueden ser desarrollados en la sala de espera. **Métodos:** Investigación descriptiva-exploratoria, con planteamiento cualitativo, realizado en un ambulatorio de atención especializada en DST/SIDA en la ciudad de Porto Alegre/RS. Los participantes fueron niños, entre siete y doce años de edad atendidos en ese servicio de salud, y sus familiares/cuidadores. Para la recopilación de las informaciones, se utilizó el Método Creativo y Sensible. **Resultados:** Del análisis temático emergieron los temas para las actividades de educación en salud. Este artículo discute los siguientes temas: sala de espera, autocuidado, salud en la escuela y representaciones de salud. **Conclusiones:** La sala de espera se configura como un espacio que puede proporcionar momento de espera agradable y productivo a través de la introducción de actividades para desarrollar educación en salud, con hincapié en lo lúdico.

Palabras clave: Niño; Enfermería pediátrica; HIV.

Corresponding author:
Paula Manoela Batista Poletto.
E-mail: paulampoletto@gmail.com

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INTRODUCTION

HIV infection under children is debit to the expansion of the epidemic amongst women, however, since antiretroviral medication, life expectation is amplified, making it possible for the child to live and grow. Parting from this amplification, preparation of the persons involved in the care and education of the children who live with HIV/aids is required to attend to demands relative to adhesion to medicine, sexuality, and other situations pertaining to this life stage[1].

There is a need to find other ways of caring, trying to understand, from the child's viewpoint, how it is to live with aids and the involvement with antiretroviral therapy (ARVT) with the idea that the stories may provide a viewpoint directed towards the necessities thus allowing to think and rethink strategies for the procurement of a quality life[2]. It is important to develop studies on this matter in a variety of scenarios, considering the specific characteristics for the age group and the complexity of the situations that the infection causes in the lives of persons[3].

In this perspective, playing is an important form of health intervention as to the child, contributing to various sectors of infant development[4]. The health professional, when developing educational health activities, making use of the ludicrous, favors popular pediatric reception in health service, as this element is part of children's life, a bridge between their internal world and the external, and essential for the understanding of self and the other[5].

Children with HIV/aids and their families/caretakers pass long periods in rooms destined to the waiting for consult or attending. The waiting rooms of services specialized in DST/aids, therefore, are spaces that promote a dialogue between the health team and the user, permitting the waiting time to be used as care strategy promoting health education, augmenting adhesion to therapies and helping the quest for quality of life for the users. The developed activities count with the participation of the health team, of civil society organizations and users of the service, and should be inserted into the ample conjunction of those that the service offers[6].

The multi-disciplinary team and especially nursing, play an important role in educational activities, in the identification of possible problems of adhesion to the antiretroviral therapy and in the intervention aiming to promote the care and adhesion to therapy by children and adolescents[7].

Thus, this research presupposition is the care, centered on the particularities of the infant with the viewpoint of children living with aids, more than the antiretroviral therapy, embracing the ludicrous as part of the children's world and of that of their families. Considering that, a health team can develop integral care in different contexts. This research proposes the development of this care in the waiting room environment.

The research objective was to understand, under the viewpoint of a child living with HIW/aids, the cares and actions in health education that can be developed in the waiting room.

METHODS

This is a descriptive-explorative research with a qualitative approach, considering that qualitative research is based on the understanding and real-life experience of people that live the phenomenon. This methodological strategy is frequently used to enlighten questions pertaining to the care practice in nursing. The qualitative descriptive approach is used to describe dimensions, variations and significance of studied phenomena. In the qualitative exploratory research, we look to unveil the ways in which the phenomenon manifests itself[8].

The participants in this research were children being attended in de health service specializing on DST/aids. Selection of participants was on invitation, on indication by the health team. The children, who, with parental consent, agreed to participate, took part in de waiting room activities during the period of information collection, totaling eight children.

Criteria for inclusion in the research were: children who live with HIV/aids under accompaniment of health service; children in the age group of seven to twelve years of age, since children aged seven or over have the ability of verbal communication and ca understand and orally express their sentiments[9]. In addition, criteria for exclusion: children with cognitive deficit or emotional disturbance making their participation in-group activities unviable. The children were included in the research independent of their understanding of aids diagnostics since this research does not aim to discuss diagnostic relevance.

The research was completed in the premises of specializes DST/aids attendance, in the Grupo de Atenção a Aids Pediátrica (GAAP) within the premises of the Children's Hospital Conceição/ Grupo Hospitalar Conceição (HCC/GHC), in Porto Alegre, Rio Grande do Sul, Brazil.

Data collection was performed using the strategy Creative and Sensible Method. This method aims at the collective construction of understanding, characterized by the valorization of singularity of each participant and collectivization of experiences[10].

The waiting room activity was developed using the Free to Create Dynamics that consists of offering a variety of ludicrous materials, promoting free artistic expression for the children to obtain qualitative data to respond to the questions of the debate[1]. In this research we offered the children coloring pencils, watercolor pens, wax chalk and cardboard. Thus, the children's productions consisted of drawings and phrases or just the drawings.

The dynamics took place in the waiting room whilst the children were awaiting consultations. Parting from the research question: "What are the cares and health education actions that can be developed in the waiting room, under the viewpoint of a child living with HIV/aids?" we opted for questions with a broader reach as to the way the child relates to its way of life: "being healthy is..." or "have a good health is...". Thus, developing the Creative Sensitive Method emerged, on the children's initiative, subjects related to health in a general sense, amongst which: facilities and difficulties of the continuing use of medication.

Hygiene, alimentation, doubts about health care at school and spare time.

Clippings from the children's stories, presented in the results of this article, stem from the presentation of their works the children held during the Free to Create Dynamics. Duration of the dynamics was approximately 50 minutes and the activity was interrupted when a child was called for consultation and continued at its return to the waiting room whilst the others continued their production. The activities were recorded in audio and took place in the second half of 2014, complying with the health service's schedule. All children that were in the waiting room took part in the activity, however, only the information of the children participating in the research was used before the signing of the Terms of Free Enlightened Consent by caretaker or family and Terms of Adhesion by the child. Ending the dynamics the registers in the field log were filled in, in order to notate for the research important observations.

The information obtained through the audio recordings over the dynamics with the children were transcribed and afterwards interpreted through thematic analysis. Thematic analyses helps the understanding of collected information this amplifying the understanding of the subject under research[5].

Considering that one of the criteria for inclusion of the participating children was to be between seven and twelve years of age, the Terms of Free and Enlightened Consent authorized by family or caretaker, was accompanied by the Terms of Adhesion of the child, both signed by participants and researcher in twofold, one copy remaining with participants the other with researcher (Resolution nr. 466/12), guarantying the identity being preserved, respecting the voluntary participation, the right of withdrawal of consent and/or adhesion at any time without personal consequences whatsoever as well as maintenance of the assistance received by the institution[11]. All The children received code names e.g. C1, C2, C3 successively up to C8, being the order of insertion of the child in the research.

The research acquired probation of the Committee on Ethics in Research of the Rio Grande do Sul Federal University (CAAE: 25944014.4.0000.5347) and of Committee on Ethics in Research of the Grupo Hospitalar Conceição (CEP-GHC) (CAAE: 25944014.4.3001.5530).

RESULTS AND DISCUSSION

Considering the objective of this research: understand, under viewpoint of children living with HIV/aids, the cares and health education activities that can be developed in the waiting room. Thus, parting form thematic analyses, emerged themes of care and action for activities in health education. This article will approach the following themes: waiting room, self-care, health at school and health representations.

Waiting room

The waiting room could be more explored by professionals in health education practices, because this space has the possibility to be more than a waiting place[12]. Health service waiting rooms are environments favorable to the development of health education activities with children, using the ludicrous as a strategy and, better still when it is possible to involve family/caretakers and health professionals in the activities[13].

The need for frequent visits to the health service interferes with the daily routine, at times making it difficult for the children who live with aids to adhere to treatment[7]. There were children and company telling they were more motivated to go to the health service when there were ludicrous activities in the waiting room[14]. In this perspective, when the waiting is idle this moment turns into a demotivating factor. Following the children tell their perceptions about the waiting:

> *I do not like (staying in the waiting room for consultation) (C8).*
>
> *Sometimes it is boring staying here and wait, there is nothing you can do. At the dentist there is a small room to play, but here I have never seen something like that (C4).*

In an randomized clinical test it was verified that the influence of ludicrous activities realized in pre-operation on children's anxiety, concluding that the participating children diminished their anxiety compared to those whose just stayed in de waiting room for ate least 15 minutes[15].

The ludicrous in the waiting room not only valor the child's developing process but is also a strategy towards health promotion as it improves communication and interaction with health professionals[16]. The children, on relating their participation in the waiting room activities of this research, show that this environment is little explored in health services:

> *I did not (participate in the waiting room activity) (C1)*
>
> *I did not (participate in the waiting room activity) (C2)*

In studies on playing in the waiting room, in the viewpoint of health professionals, it was found that the professionals recognize de advantages pf using toys, many confirmed not to use it frequently with children[16]. It becomes necessary for professional formation to include humanistic principles to stimulate creativity and adopt ludicrous strategies for the assisting children, understanding this activity as an integral part of health care for this population[16].

In moments of disconcert mediated by the ludicrous, the professionals have the possibility to interact and understand the child its proper environment Playing language provide the child with the expression of its thoughts, desires and fears and, thus, is being understood by professionals as important actor in the care process. The understanding of children acquired by health professionals can be used as tools to construct care strategies[13]. One sees the need for health actions that go beyond the therapeutic, being indispensable to focus on the stages of growth and development[5].In the following story, the child demonstrates

interest to know whether the researcher usually realizes activities in waiting rooms:

> *You always do that? (Whether the researcher always realizes activities in waiting rooms) (C2).*

In this way, here we point out that the waiting room may be theme for activities developed in this local as it enables the child to express its sentiments generated in the course of the moment it awaits consultation and its expectations as to this environment.

Self-care

For the improvement of the quality of life for the child in chronical conditions and its family, it is necessary to understand the singularity of the significant the sickness assumes in the life of the child and the family[17].Emphasize the importance of a multidisciplinary team capable of attending to the health demands specific for this population, promoting autonomy of self-care in a gradual non-imposing manner[18]. Following, the children describe activities of daily life common to all children independent of diagnostic of aids or whichever chronical disease:

> *Yes. (I brushed my teeth). [...] Taking care of teeth. [...} Three (times a day I brush my teeth) (C5).*
>
> *Brush teeth well. [...] I brush in the morning and before going to sleep (C4).*
>
> *I do not brush at afternoon lunch. [...] No (I don't use dental floss) (C6).*
>
> *Take a bath. [...] Have dinner. [...] Put on pajamas. [...] Brush teeth (before going to sleep) (C8).*

Understanding the process of care by health education, as to the use of toys is a stimulant for the child's participation in its own care, which are strategies that can help it to develop the autonomy for selfcare[17]. In foregoing stories the children describe their habits of oral hygiene ad, following, talk about their habits in corporal hygiene, demonstrating they are in a process towards autonomy of self-care, since they do not speak of receiving help when realizing these activities:

> *Every day (I take a bath) (C3).*
>
> *I take a bath each day. [...] I really take a bath (I don't pretend to). [...] One has to dry oneself, wash the head, the body (C4).*

All of the health team have to reflect the singular way in which the children in chronical conditions see their illness and its repercussions, trying to identify, by listening attentively and verbal interaction, the capacity of understanding that a child according to its age, aiming to produce a more emphatic care that attends to the necessities relative to its phase of growth and development[17]. In the same perspective as to give force to children to expose its perceptions, some authors confirm that children who perceive a family environment where they feel supported and exist a greater involvement and more liberty to express what they feel, are more normative in terms of weight class[19]. Following, the children present their perceptions of health and feeding habits.

> *Taking care of alimentation (C5).*
>
> *I drink lots of water. [...] I ate well here. [...] Eat vegetables, rice, beans, meat, carrots and a dessert (C4).*

The family/caretaker appears to be a caring person, assuming responsibility of preserving the child's life, enforcing actions of care to maintain life[5]. Thus, family care in relation to alimentation seems not only to be related to the preparing and choice of food, but is also associate with family relations and the possibility of expression for the child in its family environment. Other authors consider that beyond antecedents of excessive weight in the family, relative to a hereditary predisposition, the family environment where the child grows may either or not empower the development of unhealthy feeding habits and the reactions to feeding stimulants will be influenced by affective and relational matters[19].

Contrary to the previous stories that presented care with food health, the following stories approach preoccupation that the children construct about the need of their families to also develop healthy habits The largest family interaction relates in a positive way to the style of a more healthy alimentation and behavior that radiate a more controlled ingestion, indicating the importance of family relations in the development of a healthy weight. An environment characterized by the relational closeness, mutual support and capable of proportioning to the child a free expression of sentiments, facilitate a more healthy physical and psychological development[19]. In the first following story the child speaks about unhealthy habits of its brother; in the second story, the child considers that being healthy is to have low consumption of sugars, because its mother has restriction of glycose consumption and the child helps her to control.

> *That's my brother, he smokes pot and drinks. [...] Stop smoking and drinking and start eating more fruit, drink less juice, that sort of thing (for my brother to regain health). [...]My grandmother does that (prepare healthy food) for me (C2).*
>
> *Eat healthy food, just that. [...] Eating vegetables is good for your health, eating fruit is good for your health, eating rice and beans is good for your health, not eating sweets is good for your health as is not drinking too much juice. [...] All (types of juice because of the sugar) (C1).*

The foregoing story shows that the caring family also develops in the child, and not only in itself, the care for its members. The family is he central element in caring as it is the place for growth and developments of its constituents besides

being responsible for the production and managing daily care to each of its members. This occurs parting from a framework of care that is being constructed during family life and based on interactions with significant persons[20]. The family context is a place that inspire affections, care and cultural patterns, thus:

> *[...] this dynamics sets in relational processes, like proximity, emotional support, mutual support, promotion of autonomy, of the capacity to think and express emotions. [...] we may be led to say that eating for the child may on one hand be the way it finds to structure itself in a family that has no affection. [...] and, on the other, a way of using the body as protection of a dysfunctional family environment*[19:50].

In the following stories the participants reveal restrictive feeding habits, limiting the ingestion of alimentation important to its growth. And analyzing the stores under the viewpoint of mentioned authors, these habits relate to the want of family relations important as well for its social development.

> *I drink milk (for breakfast) [...] I don't like salad (C7).*
>
> *It's good (to eat fruit). Banana (is the fruit I like the most). Not any (vegetable I like). [...] Hot chocolate with banana (for breakfast). [...]I like one thing too, I like sauce, chocolate sauce from cakes (C8).*

Giving the child the opportunity to express its perceptions another theme that may be approached emerged in the waiting room activity: Self-care.

Health at school

The way the child deals with its sickness, its marks and consequences, will reflect in all areas of their lives. Family and school represent the principal places of sociability, and for children who live with illness are the first places where the means of dealing with the illness begin to be constructed or eleborated[4]. School is a privileged place to promote health and to prevent downfall of health and illnesses:

> *The Program Health at School (PHS) contributes to the reinforcement of actions in the perspective of integral development and proportion the school community with participation in programs and projects articulating health and education, to confront vulnerabilities that compromise the full development of children, adolescents and youth in Brazil. This initiative recognizes and embraces integrating actions between health and education already existing having a positive impact in the quality of life of those being educated*[21:6].

This strategy has contributed to the incentive of teachers to develop and implement local actions at schools, in a participative and constructive process. Promotion of health education in school environment is e process under permanent development[22]. In the following story the child considers the school to be also a place to learn about health:

> *Yes, (I learn about health at school) in science class (C5).*

These processes have to be capable of contributing to the acquisition of competences, permitting the children to confront themselves in a positive way, construct a project for life and be able to make individual conscious and responsible choices[22]. At school promotion of health with those being educated as well as teachers and staff, has to have as starting point "what they know" and "what they can do"[21].Promotion of health education at school, has also a mission of creating facilitating environments of the schools and stimulate critical spirits exercising citizenship[22].

Insertion of health education activities at school may well be a tool that promotes dialog and critical reflection of the aids stigma, aiming to integrate the individuals completely in the community in which they live, minimalizing discrimination and preconceipt[18]. It is therefore necessary to develop in each one the capacity of interpreting daily life and act in a way as to incorporate attitude and/or behavior adequate to improve the quality of life[21]. Health and education professionals have to assume a permanent attitude of empowering the basic principles of health promotion of teachers and staff of the schools[21]. School is a place where the child besides apprehending cognitive abilities develops and establishes social aliances[23]. And the children participating in the research recognize the school environment as a place for socializing, important to its development:

> *Aham (going to school is important for your health). [...] You must know that, to learn to write to work (C4).*
>
> *(Going to school is important for one's health to) play, study. [...] Play (is what I like to do at school intervals). [...] I eat too (C8).*

The school environment presents itself as another possible theme for activities if health education in the waiting room.

Health representations

Face the child's production seriously means considering it a rightful person[4]. Thus the stories of the children relative to what they think of being healthy and have a good health escapes from clinical questions relating intrinsically to the perspective of amplified health. The children approach a variety of themes to explain what is to them "being healthy" or "have a good health".

> *Taking care of the environment. [...] Study (C5)*
>
> *Here I watched TV. [...] Because I am fond of watching TV, at times I watch the news about what happened in the world (C4).*
>
> *A book (C3).*

Health has to be understood in an ample manner and include from care essential to maintain life to that relative to its quality, embracing the area of affective interactions[20]. Daily life of children living with HIV/aids is fll of situations that promote its growth and development, for instance the toys they prefer[3]. Here the children point to the diverting activities:

> *This drawing is my little sister. [...] I will have (a sister). She is not born yet. [...] (O drew) sis' little bed. [...] (This) is me with sis (C4).*
>
> *I drew a game of basketball. [...] Only at school (do I play basketball). Friends (are the players in the design who will have names). [...] To play (is to be healthy) [...] That is basketball and that is soccer (C8).*
>
> *This here is a cap (about a boy with football at its feet) [...] Yes (I play soccer) [...] I practice jiu-jitsu. [...] They are (healthy persons who practice jiu-jitsu). [...] Who smiles (is healthier than who does not smile) (C6).*

The nurse has the task to implement and promote means by which the toy can be incorporated in the care, respective to the child and its family needing of health care, so the child may maintain its growth and development in a healthy way, reverting the experience of getting ill into benefits for its maturation[24]. The health team valorizing the play, the ideas and desires of the children as ways of being that influence directly its growth and full development. It is, thus, important to proportion the child and its caretakers with a dialog in which they may discuss question involving he health/illness process in it social and existential dimensions[3].

Thus, possibilities arise for actions in health education, as shown here, in another theme for activities in health education in the waiting room - the representations of children's health.

CONCLUSIONS AND PRACTICE IMPLICATIONS

Considering the chronical characteristics of aids, and, consequently, the implication of visiting the service uncountable times, it is unavoidable that the health professional makes use of all opportunities for contact with the child and its family/caretaker to prevent comorbidities and promote health.

The waiting room environment is a very good moment for health education with an emphasis on the ludicrous. Besides the possibility to promote and prevent health, the presence of activities in the waiting room makes the service cozy for the children who live with aids as well as for their family/caretakers, motivating this pair to frequent the health service and diminishing the anxiety generated by awaiting attendance.

Ludicrous activity in the waiting room, in the waiting room environment, improves the interaction between health professionals and the child living with aids, besides giving the professional the possibility of giving voice to the child and so getting to know it, generating more singular therapeutic plans. For health education to take place in this environment it is imperative to pass the barriers and create a contemplative environment: an adequate and ludicrous space, disposal of a professional to conduct the activities, a professional health team open to the ludicrous, strategies of comfort for the child as to diminish or avoid inhibitions to participate in the activities.

Starting form possible themes for the care and actions in health education at giving voice to the children, the necessity of approaching with the child themes common to caring of the health of children with chronical illnesses. In this way, it becomes necessary to have a health professional in the waiting room to conduct the actions of health education. In this respect, the nurse in a multidisciplinary team identifies as a professional qualified to this function, due to formation and qualification for health education. The waiting room activity approximates the child's nurse and family, facilitating the expression of sentiments, thoughts and emotions that constitute unavoidable factors in the relation caretaker-caregiver Thus creating means for the children and families to feel supported and confident to openly discuss the therapeutic plan free of preconceptions.

As a resource, there is also the Dynamics of Creativity and Sensibility, for activities in health education in the waiting room, favoring the individual expression of each child and the collective construction of knowledge admissive to children's language that is produces in the exchange of children's wisdom with the health professional. Participants unanimously expressed content with the health education activity whilst awaiting consultation, making the waiting room not only a place of research but also more than anything else a place for interventions in health as the activities transform the health environment.

It is necessary to reflect the waiting room as an underlay for health education because this environment can constitute e network of support for the children living with aids, permitting them to write their own history and a way of singular care of its necessities when given voice to its experiences, valorizing the necessity of expressing through the ludicrous.

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