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CHRONIC DISEASE IN CHILDHOOD ANDADOLESCENCE: FAMILY BONDSIN THE HEALTHCARE NETWORK[1]

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ABSTRACT

Objective: to explain how the bonds between the family of the child/adolescent with chronic disease are created and the different services of the health care network, having the Primary Health Care as the organizing center for care.

Method: qualitative approach study, carried out with ten family members of children/adolescents diagnosed with a chronic disease between May and November 2015. In order to produce the empirical material, the talking map and the ecomap have been used, both adapted in this study, in their homes, located in the area covered by the Family Health Units and in the Family Health Unit itself, according to a family member's preference. Subsequently, twelve semi-structured interviews were carried out with professionals of the city's healthcare network - two Family Health Units and two public hospitals. The data were interpreted based on the French line discourse analysis.

Results: the sense of bonding is related to the care and attention provided by health professionals. The care presented in the textual marks analyzed is a basic concept, which can be paraphrased in its several meanings, such as: accessibility, resoluteness, accountability, humanization, empathy and satisfied expectation.

Conclusion: it is necessary that each care point of the healthcare network sought by the family is a broad, concrete and lasting reference, especially the Primary Health Care, which should fulfill its role of a care coordinator and caregiver source.

DESCRIPTORS: Child's health. Adolescent's health. Chronic disease. Professional-family relations. Health services.

DOENÇA CRÔNICA NA INFÂNCIA E ADOLESCÊNCIA: VÍNCULOS DA FAMÍLIA NA REDE DE ATENÇÃO À SAÚDE

RESUMO

Objetivo: explicitar como se constroem os vínculos entre a família da criança/adolescente com doença crônica e os diferentes serviços da rede de atenção à saúde, tendo a Atenção Primária à Saúde como o centro organizador do cuidado.

Método: estudo de abordagem qualitativa, realizado com dez familiares de crianças/adolescentes com diagnóstico de doença crônica entre maio e novembro de 2015. Para produzir o material empírico, utilizaram-se o mapa falante e o ecomapa, ambos adaptados neste estudo, em seus domicílios, localizados na área de abrangência de Unidades de Saúde da Família e na própria Unidade de Saúde da Família, conforme preferência de um familiar. Posteriormente, foram realizadas doze entrevistas semiestruturadas com profissionais de serviços da rede de atenção à saúde do município - duas Unidades de Saúde da Família e dois hospitais públicos. Os dados foram interpretados com base na análise de discurso de linha francesa.

Resultados: o sentido de vínculo está relacionado à atenção dispensada pelos profissionais de saúde. A atenção explicitada nas marcas textuais analisadas é um conceito base, que pode ser parafraseado em seus vários sentidos, como: acessibilidade, resolutividade, responsabilização, humanização, empatia e expectativa satisfeita.

Conclusão: é preciso que cada ponto de atenção da rede assistencial buscado pela família lhe seja uma referência ampla, concreta e duradoura, especialmente a Atenção Primária à Saúde, que deve cumprir seu papel de coordenadora do cuidado e fonte cuidadora.

DESCRITORES: Saúde da criança. Saúde do adolescente. Doença crônica. Relações profissional-família. Serviços de saúde.

ENFERMEDAD CRÓNICA EN LA INFANCIA Y ADOLESCENCIA: VÍNCULOS DE LA FAMILIA EN LA RED DE ATENCIÓN A LA SALUD

RESUMEN

Objetivo: explicitar cómo se construyen los vínculos entre la familia del niño/adolescente con enfermedad crónica y los diferentes servicios de la red de atención a la salud, teniendo la Atención Primaria a la Salud como el centro organizador del cuidado.

Método: estudio de abordaje cualitativo, realizado con diez familiares de niños/adolescentes con diagnóstico de enfermedad crónica entre mayo y noviembre de 2015. Para producir el material empírico, se utilizaron el mapa hablante y el ecomapa, ambos adaptados en este estudio, en sus estudios en el área de cobertura de las Unidades de Salud de la Familia y en la propia Unidad de Salud de la Familia, según preferencia de un familiar. Posteriormente, se realizaron doce entrevistas semiestructuradas con profesionales de servicios de la red de atención a la salud del municipio - dos Unidades de Salud de la Familia y dos hospitales públicos. Los datos fueron interpretados con base en el análisis de discurso de línea francesa.

Resultados: el sentido de vínculo está relacionado a la atención dispensada por los profesionales de salud. La atención explicitada en las marcas textuales analizadas es un concepto base, que puede ser parafraseado en sus diversos sentidos, como: accesibilidad, resolutividad, responsabilización, humanización, empatía y expectativa satisfecha.

Conclusión: es necesario que cada punto de atención de la red asistencial buscado por la familia le sea una referencia amplia, concreta y duradera, especialmente la Atención Primaria a la Salud, que debe cumplir su papel de coordinadora del cuidado y fuente cuidadora.

DESCRIPTORES: Salud del niño. Salud del adolescente. Enfermedad crónica. Relaciones profesionales-familiares. Servicios de salud.

INTRODUCTION

Chronic diseases are characterized by their gradual onset, usually having an uncertain prognosis, with long or indefinite duration. They present a clinical course that changes over time, with possible periods of exacerbation, and may lead to disability. They are responsible for the large number of hospitalizations and require a continuous care process that does not always lead to the cure.[1] The health care of people with a chronic disease must be carried out in a continuous, coordinated and comprehensive way, so that the demands triggered by the chronic disease are minimized.

The life of children/adolescents and their families, from the diagnosis of a chronic disease, is then guided by the disease and its treatment. It translates into a long route, permeated by difficulties, and by feelings that are represented by the anguish and uncertainty.[2]

The comprehensive care provided to individuals with chronic diseases should be based on the continuous and proactive monitoring of these subjects. This care must be carried out under the coordination of the Primary Health Care (APS - *Atenção Primária à Saúde*) team and with the support of the other healthcare network services.[3]

The Healthcare Networks (RASs - *Redes de Atenção à Saúde*) have emerged as a strategy to overcome the fragmentation of care and management in health regions and to improve the institutional political functioning of the Unified Health System (SUS - *Sistema Único de Saúd*e). The objective was to provide the user with a set of actions and services that they need with effectiveness and efficiency.[1] The organization of the system in networks promotes the continuous and comprehensive care for a specific population, coordinated by the APS, provided at the right time, at the right place, with a proper cost, with the adequate quality and in a humanized way.[4]

The APS needs to be the gateway for users into the health system. It needs to provide the continuity and the coordination of care of chronic diseases in childhood and adolescence, since these are essential components for the high quality of the service provided.[5-8] Despite this, studies indicate that, not always, the primary care is sought by families in an episode of illness,[9] which makes it impossible to create a bond with this service and what leads to the non-recognition of the APS as a caregiver source.[5,7,9]

The bonding is an innovative relational technology to organize care, which can transform work processes, making them comprehensive in health.[10] The promotion of care encounters centered on creating bonds should be one of the priorities of the healthcare teams in the healthcare network. However, families of children/adolescents with a chronic disease have pointed out obstacles in this process. Among these obstacles it is possible to mention the lack of accessibility, lack of responsibility for the care, lack of resoluteness, lack of knowledge about aspects of chronic illness, and the direct search for specialized services.[5-7]

From the reflections presented, it is questioned: how are the bonds created between the family of the child/adolescent with a chronic disease and the different services of the healthcare network, having the APS as the organizing center for care? To answer this guiding question, the objective was to: explain how the bonds between the family of the child/adolescent with a chronic disease and the different services of the healthcare network are created, having the APS as the organizing center for care.

METHOD

Qualitative approach study, based on the French matrix theoretical-analytical device of the Discourse Analysis (DA),[11] carried out in from May to November 2015, in a municipality of Paraíba, with ten family members of children/adolescents with diagnosis of a chronic disease in their homes, located in the area of coverage of the Family Health Units (USFs - *Unidades de Saúde da Família*) and in the Family Health Unit itself, according to a family member's preference. Twelve health professionals in their workplaces have also participated in the study: USFs, Pediatric Outpatient Clinic and Pediatric Inpatient Clinic of two reference hospitals in the state for the treatment of chronic and rare diseases.

The inclusion criteria of the family members were defined a priori. They were: being related to a child/adolescent with a diagnosis of chronic disease; being one of the main responsible for caring for the child or adolescent during the course of the disease; having the ability to understand and express what is required in order to build the research process. The exclusion criteria were: being related to a child or adolescent with a chronic disease hospitalized during the period of the empirical material production and not being at home due to the daily work routine.

The production of the empirical material with the relatives happened through the construction of the talking map,[12] as a nuclear technique, and the ecomap was used as complementary technique,[13] both adapted in this study. Although the technique of building talking maps is more commonly used in groups, it has been adapted to be applied with family members individually. The adaptation of the ecomap has occurred because it has a specific focus on the registry of the family bonds with the health services and professionals that are part of the healthcare network to the child/adolescent with a chronic disease, without considering the relations between the family and the environment where they live.

After elaborating the talking map and the ecomap with the family members, the services and health professionals that have or have not established bonds with the children/adolescents and their relatives were identified. Therefore, health professionals who were representatives of these services were sought.

The inclusion criteria for health professionals have also been defined a priori. The conditionality was to be working in the health service referred by the family members for more than six months in the position, and to care for the children/adolescents with a chronic disease in their daily work routines. The exclusion criteria were:professionals who were away from the service during the period of collection of the empirical material, for reasons such as vacations, leave and/or medical certificate.

The technique to produce the empirical material based on the statements of the professionals was the semi-structured interview.[14] It was recorded and transcribed in full for further analysis. The closure of the production of the empirical material followed the criterion of sufficiency, when it is thought that with the empirical material it is possible to draw a comprehensive picture of the object of study.[15]

In order to analyze the empirical data, the theoretical assumptions of the DA, which emerged in the late 1960s in France, organized by Michel Pêcheux, who articulated the concepts of language, ideology and subject were used.[16-17] In the discursive perspective, the proposal is to explain the processes of meaning production, in the relation between language, ideology and individual, in order to understand how the language produces meanings by and for individuals, since there is no discourse without an individual and there is no individual without an ideology.[11]

In the first stage of the analysis, the conditions of the discourse production were observed. The meanings produced are not only in words but also in their relation with the circumstances and context in which communication takes place.[11] The individualswere the enunciators of the study, nine mothers and an aunt of a child/adolescent with chronic disease, ranging in age from 30 to 47 years old, and monthly income from $ 450 to $ 5,000.00. The diagnoses of the children/adolescents were: cystic fibrosis; systemic erythematosus lupus; cerebral palsy; congenic cardiopathy; chronic asthma; chronic nephropathy; Rett's syndrome; systemic arterial hypertension; type 1 diabetes mellitus; congenital heart disease, and renal tumor. Regarding the time of diagnosis, it varied from one to 15 years.

Were also enunciators of this study: five professionals from USFs, two nurses, two community health agents (CHAs), one physician; three specialized outpatient professionals - a nursing assistant, and a social worker, a physiotherapist; three professionals from pediatric inpatient clinics - two nurses and one nursing technician; and a physician who works in the same institution, both in the outpatient clinic and in the pediatric inpatient clinic. The age of these professionals ranged from 30 to 62 years old, and the service time ranged from seven months to 23 years.

Several readings were made: of the transcribed texts, raw empirical material, composed by the full transcription of the application of the talking map and the ecomap with the relatives of the children/adolescents with chronic disease, and the interviews with the health professionals. Then, the *corpus* was constituted, formed by discursive fragments related to the object of the investigation which, when analyzed, explicit the meanings by using the heuristic questions, in a constant coming and going between theory and analysis.[17]

In the analysis process, the first heuristic question is: "What is the concept-analysis in the text?" In this study, the concept-analysis was defined a priori:[17] bonds between the family of the child/adolescent with a chronic disease and the healthcare network services. Then, the textual marks with which it is possible to evidence the constructed meanings in relation to the proposed concept-analysis were identified, in order to answer the second heuristic question: "How is the concept-analysis being constructed?". From the verification of the recurrence of these marks, the third heuristic question emerged: "What discourse supports this sense?", aiming to relate the constructed meaning with the discursive and ideological formations that support it.[17]

It should be emphasized that it was not possible to include discursive fragments of all the enunciators in the text, due to the limited space for the elaboration of the article. However, all the participants were included in the analysis and contributed to build the knowledge on the theme.

In compliance with the Resolution No. 466/12 of the Ministry of Health, which regulates the research involving human beings, the study obtained a favorable opinion from the Research Ethics Committee (protocol No. 054/14, CAAE: 27102214.6.0000.5188). All the research participants have signed the Free and Informed Consent Term.

In order to preserve the anonymity, the following identification form was adopted: for the family members, the initial F, followed by the ordinal number that represents the order in which the interviews were carried out was used (F1, F2, ... F10); for the health professionals, the professional category was used, followed by the service where the person works (Nurse - USF 1), and so on.

RESULTS

Discursive block: Actions that favor the construction of bonds

The subject's discourse makes it clearthat the creation of bonds starts with the search carried out by the relatives of children and adolescents with a chronic disease due to their resoluteness and signifiers of care in the healthcare network: *I went to the PSF* [USF], *which is where we always go when we have something. My little girl started with spots on the skin.* [...] *There* [USF] *the doctor referred me to the C.C.* [municipal outpatient clinic]. [...] *From the C.C. I was referred to the H.V.* [pediatric hospital], [...] *they tested her again, and the tests only diagnosed low platelets and leucocytes, I went through the pediatrician with her*[adolescent]*: It is dengue.* [...] I *did not believe it was dengue, I went to the PSF and they referred me to the C.C. again,* [...] *that was when he* [pediatrician] *said: 'Probably, your daughter has Lupus'* (F2). *The health unit* [USF] *did not solve, because it was not their case* [child] *it was serious, I had to go to the hospitals, I went to the A.* [pediatric hospital], [...] *a few days later he had other crises, I went to another hospital, since the other did not solve it, until I got to the right one.* [...] *After I met this doctor* [specialist doctor], *he did not have another a strong crisis* (F5).

It is possible to observe that the bonds in the healthcare network are created based on the attention that the family receives from the health professionals when they look for the services. This attention has several nuances and stands out in the textual marks that follow the accessibility as a form of attention and care: *We have no difficulty accessing him* [specialist doctor], *even at home, if you need, you can call, because it is hard for you to have a doctor who gives so much attention.* [...] *This makes us very safe* (F1). *If you wait for the system this child* [with a heart disease] *most of the times dies.* [...] *And in order for that not to happen, we make the fitting, I authorize the staff to schedule the consultation for these children, because the important thing is not the bureaucracy, the important thing is the life* (Social Worker - Pediatrics Outpatient Clinic 2).

The discursive fragments that follow show that the creation of bond is also related to the resoluteness that family members find within the healthcare network. In order for the family to return to the service, it must be a reference for continuous care, so that their needs are at least minimized: *She* [CHA] *is the one who is always present,* [...] *she never fails to come to my house, when I have a problem, I look for her because she will provideus with a better guidance*

(F6). *The family needs to know that you want to solve the problem, and that you take action to solve the problem, from an exam referral inside the hospital, and even to fight in court to get medicine.* [...] *Because the family, by trusting, will come more to the service and, by coming to the service and seeing that the service wants to solve the problem, does not solve in an absolute way, because we know we are not talking about a disease that has a cure, we are talking about solving the problem regarding accessibility to all forms of treatment of it* (Doctor - Outpatient Clinic and Inpatient Clinic 1).

The qualified listening and emotional support that family members receive from the health services also constitute actions that favor the creation of bonds, since the focus of care lies in the singularity of each encounter between the subjects: *Sometimes we think we only help by giving medication, but often by listening to their home problems, their fears,* [...] *just the fact that you listen, sit and allow the mother or father to sit down and tell their context, talking about their difficulties and supporting them in some way, even if you still do not agree, for him I think it is already a great help* (Nurse - USF1). *When they are going to provide care, sometimes, by SUS, they do not pay much attention, they do not explain, they do not have much patience. He* [specialist doctor] *provided care and asked me well from the time I went to a private consultation, and when I went to SUS, he provided the same care.* [...] *I saw no difference, I saw the same zeal.* [...] *The same love, of looking in the eye, stopping to hear you* (F3).

Although the offer of support is recognized as an action that favors the creation of bonds, the enunciators recognize that this ability is intrinsic to the way of being of each health professional. This is because the humanization and empathy present in the relationships are proper to each individual: *Either you are human or you are not, but when you are human, you do it because that is what you like to do.* [...] *To be human is to know that we are here, to see a mother who is ruder, or who has treated us badly, but she is here every day, her son is sick, we are not.* (Nursing Technician - Pediatric Inpatient Clinic 1). *Empathy is within you, as you are, so that you can transmit what you have inside of you.* [...] *For our children, we will try to treat them well, play as much as possible, distract them, especially during a painful procedure* (Nurse - Pediatric Inpatient Clinic 2).

Discursive block: Actions that make it difficult to create bonds

Among the actions that may make it difficult to create bonds, the lack of access to the health services was evidenced, both in the APS and in secondary and tertiary care, which leads the family to trace their own trajectory in the healthcare network, which is revealed as a marker of vulnerability of the families that experience the chronic disease: *He only sees* [doctor] *twelve people, if he gets one more sick person, he will not see the person.* [...] *And the person having to suffer 'Oh, go to UPA* [Emergency care unit], *go anywhere...', for God's sake, it is a health unit* [USF], *it for the neighborhood, the doctor has to be available there.* [...] *We feel humiliated to know that it is that station that is there to serve you well and you are not cared for* (F3). *When you arrive to fill in the form is already a delay.* [...] *It cannot be characterized as bad* [service], *because he* [child] *left after receiving care,* [...] *I had no money, I had to submit my son and myself to a public service* (F6).

The challenges are also related to the way that care is provided in the health services, which often does not have a broad and comprehensive view and is limited to focusing on the child/adolescent's disease, excluding the family from this process. She also needs care, from what she experiences, along with the child/adolescent, the implications of the chronic disease: *It is aimed* [the attention] *at basically the health problem, it often does not involve him* [child/adolescent] *as a whole, it also does not focus on the family.* [...] *The focus is on the pathology, it is more in relation to the drug treatment, to stabilize. If it is stable, the patient is discharged* (Nurse - Pediatric Inpatient Clinic 2).

In the hospital environment, a factor that hinders the creation of bonds is the conflicts between the health team and the family members who accompany the child/adolescent. The physical and emotional exhaustion of these caregivers, as well as the work routine of the team, make these subjects susceptible to conflicts: *A patient that from the birth to the first year of life stayed here, and the mother never went home, is it a good relationship? It has to be, but there will be times when both the patient and the companion will be really worn out, but from the moment that the child starts to be manipulated by the team,* [...] *and there is no immediate improvement of the condition, it ends up in some misunderstanding. Sometimes because these family members understand that the failure in the improvement of the condition is responsibility of the team.* [...] *We try, in most cases, to have a good relationship because we need to have this family member as our ally in the care of that child, so it is necessary to take a deep breath, be patient and deal with this process in the most serene way possible, if that is even possible* (Nurse - Pediatric Inpatient Clinic 1).

A factor that makes it difficult the creation bonds between health professionals and the family is the lack of information about the care provided.

This causes concern and insecurity: *It concerns me that in A* [support institution for people with special needs] *we do not get in, she* [child] *goes to receive care, I leave her at the door, she goes in there and I do not even know what they are* [physiotherapist and speech therapist] *doing, one day or another somebody says something* (F7).

The medical care provided in the APS, based on lack of listening and sensitivity to the user's problem, distances the family members of children and adolescents with a chronic disease from the service and leads them to the non-recognition of the APS as a caregiver source, nor as a care coordinator: *I entered the office with R.* [adolescent], [...] *She* [USF doctor] *started saying: 'I am seeing you and you are still talking?'. That was when the crying came. 'And you are going to cry?'* [...] *I have not been there again, when I wanted care, I used to look for the H.V. pediatricians.* [pediatric hospital] (F2). *It should not be another consultation, but a welcome, an embrace, If you came here it is because you need help, and we do not find this, we only find a doctor there* [at USF] *'Tell me your problem, what do you need?', I will prescribe* [medical prescription], *you are talking and prescribing.* [...] *You cannot find a human doctor* (F3).

The fact that health professionals, especially those from the APS, do not know the singularities of chronic diseases constitutes an obstacle to the effective construction of bonds, because it is not possible to offer a solution to the demands presented if the families do not believe in the care offered in the service. The lack of preparation to deal with chronic diseases in the APS leads families to seek care only in the secondary and tertiary care services: *When I would talk to a nurse, a health agent about cystic fibrosis, they did not even know what it was.* [...] *I explained that it was a rare disease, but they* [USF professionals] *do not have information, the information they should have they do not have* (F1). *M.* [CHA] *said: There is a girl in our area with Rett's syndrome. I say: My God, what is that? Later, the girl got sick and it started here, if I am not mistaken, they came a few times, I still have not gotten the medical record.* [...] *I have not researched it yet, I know it is a neurological disease, I asked Dr. J.* [USF doctor], *but she did not know how to explain it to me either* (Nurse - USF 2). *If you are a healthcare professional and a new disease appears, you have to search and have to care because the basics I believe you learned in university.* [...] *Because nobody knows everything, but you cannot deny care, who is from the health area takes an oath right?* (F4).

Another factor that is an obstacle in bonding is the lack of accountability of health professionals, especially in the APS, because they believe that the day-to-day care is the responsibility of the family. Thus, they deny their role in the coordinated and continuous follow-up to the child and adolescent with chronic disease and their family: *I forgot his name* [child with hypertension], *it is from F.M.* [street where the child lives]. [...] *The mother is not interested.* [...] *It is a child who has conditions, the family is able to walk, to look for it, I do not only have this one.* [...] *It is a lack of will of the parents, and then every care has a certain limit. We cannot carry. It is not because we gave up, but... I believe she has not been caring for this boy* (Nurse - USF 1).

DISCUSSION

The discursive analysis of the textual mark on the search for the diagnosis of the chronic disease and the adequate therapy shows a valorization of the APS as a first contact access for SUS. This valorization is built through an interdiscourse that is sustained, probably, by previous experiences of the enunciator in the APS itself. However, implicitly, the discourse demonstrates the fragmentation of the care provided in the healthcare network, because, even with referrals, there was no family follow-up service in this process, and the mother traced a lonely path for health services.

On the contrary, discursively analyzing the second statement, there is a strengthening of the discursive memory that only hospitals can solve health problems. This is a discourse centered on the hospital-centered model, on the hegemonic medical care, accentuated by the disbelief in the care provided by the APS. Thus, the bond between the family and the APS team is weakened, at the same time the bonds with secondary and tertiary care points of the healthcare network are favored.

A study[5]corroborates the findings of this research, concluding that the APS health team does not feel responsible for coordinating the care of people with chronic diseases and delegates to the family the task of finding the best way to care, which does it most often in secondary and tertiary healthcare network services.

With the intention of minimizing the problems triggered by the fragility of the regulation of vacancies, which can negatively affect the health and well-being of children and adolescents with chronic diseases, as well as their families', and aiming at offering access and continuity of the care, some specialist doctors launch strategies to promote the follow-up of these individuals. As an example, through the scheduling of return consultations without having to go through the regulatory system and the provision of private contact numbers for urgent cases.[7] This action strengthens the bonds with these professionals, because the family recognizes them as a caregiver source.

Some enunciators, despite living in different social contexts, attribute senses and meanings that are similar to accessibility as a favoring action for the creation of a bonding. This is especially true when they relate the care to actions that go beyond the limits of hard-working care technologies, with the valorization of live work, to the detriment of bureaucratized actions.

In the F1 statement, *because it is hard for you to have a doctor who gives so much attention*, the discursive memory of the enunciator is highlighted, and her speech denotes the silencing of previous experiences that made her link with the specialist doctor, because he broke with the image built previously, of a physician, and started offering security in the care provided to her daughter and, thus, favoring the creation of bond.

The healthcare needs to be centered on the live work. It is necessary to provide healthcare with priority for relational technologies, and every health professional, in their act of caring, should be able to promote them, in order to favor the creation of bonds, accountability, autonomy and acceptance.[18]

The senses and explicit meanings about the resoluteness as a form of care, attention and of the creation of bonds are related to the trust acquired in the health professionals from the moment when the relatives have their demands met. The relationship between resoluteness, accountability and trust in care is implicitly understood, which are fundamental for creating bonds in the care network.

A horizontal relationship between health professionals and those experiencing a chronic disease, through an effective dialogue during the care meetings, helps users build trust, strengthen bonds and create spaces where they feel respected and unique. A study[19] corroborates these findings when states that, in addition to the resolution offered, the manner this interaction happens determines how the bonds will be created. Another study[20] highlights that, if there is trust in the bond, the subject receiving the care becomes more accessible to the dialogue, because he/she feels that he/she can expose his/her demands to the professional, and this allows a more comprehensive attention. Therefore, the bond depends on relational technologies.

It is also important to highlight the importance of the health agents in creating bonds in the APS. The health agent's constant contact with families can help identify children and adolescents with chronic diseases and indicate the need for interventions. Therefore, the CHA is an important mediator in the healthcare network insofar, as it facilitates the access of the child/adolescent and the family to the health services.[9]

The singular dialogical relations from person to person, the ability to commit to the real conditions of the family, the establishment of affective and effective exchanges,[21] the qualified listening without hierarchies and impositions and the respect are actions developed during the interaction of the professional with the user, which can promote the emergence of an effective bond between the subjects,[20] making it possible for this professional, with whom the family of the child/adolescent with chronic disease has established a bond, to be a concrete and lasting reference for qualified care.

Some discourses are supported by an ideological affiliation, which is close to the appreciation of the care centered on qualified listening, on uniqueness and humanization. However, there may be gaps in these discourses, which materialize in the contradiction of meanings, because in the same discourse fragment, the punctual and curative character of care is configured, which makes the care fragmented and incapable of being comprehensive, especially in the APS.

The market ideology supports the construction of some discourses, because for the relatives, in the current conjuncture, only the private service can solve the health needs. However, there is a rupture in this perception, when the same specialist doctor offers care in both the private network and in SUS, and aims his actions in qualified listening and in the humanization of the care provided.

In relation to the healthcare, there is a strong link between the expansion of medical services and the capitalist advancement, manifested in the development and strengthening of the medical-industrial complex,[22] which is why it is essential to qualify the public health service and transcend the capitalist appreciation of care. For this, it is necessary to transform into actions all the precepts that constitute SUS.

The linguistic materiality, when analyzed in the textual fragments of the nursing professionals about humanization and empathy, who provide care to those who experience chronic diseases in childhood and adolescence, denotes, through the non-said, that there is a disbelief in the possibility of changes in the subjects' behavior. It is also possible to infer that the creation of bonds depends on the way of being and on the unique actions of each professional during the consultation with the family members.

The discursiveness of some family members of children/adolescents with chronic diseases is strongly marked by the expectation not met, both in the APS and in other points of the care network, as well as by the submission to a public healthcare network due to the lack of financial resources to find other care sources. These families mention that the network is not able to serve them effectively, and they become vulnerable and suffer damage to their physical and mental well-being, which also affects children and adolescents.

The difficulty in accessing the healthcare network is an important marker of vulnerabilities experienced by families, especially regarding programmatic vulnerabilities. These occur when the health services have inadequate organization and management of resources. This way of organizing the work damages the quality of care offered and causes the child/adolescent and the family to become victims of a situation that is beyond their control.[23]

Although the family bonds are more effective with the secondary and tertiary healthcare services of the network, there are actions in these services that hamper or weaken the bond with families. In the speech of an enunciator who works in a hospital institution, she refers to the non-concern regarding the comprehensiveness of the care offered, with a discursive formation centered in the health-disease process, which hinders the possibility of trusting, acquiring security, and of creating links.

The comprehensive healthcare requires family-centered care. Its emphasis is on the mutual collaboration between patients of all ages, families and professionals in the healthcare network and in every health institution.[24] Both the child/adolescent and their families have care demands that deserve the attention of health professionals. This will only be possible through the qualified listening to the needs of the family, support in their choices and guidance in the search for ways to strengthen the family regarding facing the daily routine of the child's disease.[25]

The senses and meanings that emerge when analyzing the textual mark related to the conflicts in the hospital environment denotes a discursive formation of imposition, since there is an unconscious gap, regarding the perception that the relationship between the professional and the family is good, because it has to be. This requires a daily effort in favor of this good relationship.

The conflicts that arise in the routine of hospitalization can interfere in the creation of bonds and impair the quality of care. Some of them are marked by insufficient information, lack of dialogue, lack of sensitivity of the professionals in relation to the moment experienced and the establishment of difficult interpersonal interactions.[25]

The discursive analysis of the F7's fragment, in which the mother demonstrates the lack of information she has received about the care provided to her daughter, allows the inference for the identification of the non-said, that the information related to the care allows the construction of trust in the work performed by the professional. When it does not happen effectively, it causes the distancing between the subjects and the construction of bonds is interrupted.

The effective communication, with exchange of information, is essential for the interaction between parents, child/adolescent and health professionals, since accessible explanation and with understandable language significantly influences the possibilities of understanding and learning, favoring the continuity of care by the family.[8]

When analyzing the linguistic materiality of family members of children and adolescents with chronic diseases, it is possible to explain the senses and meanings constructed at the level of oblivion number 2. According to the DA theory, it is in this oblivion that the subject selects, in an unconscious process, what they are going to say.[11,17] It leads us to infer that the medical care received, most of the time, is inhuman and provided to families as a favor.

The doctor's figure is valued in their hegemonic and medicalizing social role, which is demonstrated in a socially constructed discourse and sustained by an ideological affiliation, within the scope of oblivion number 1, when the subject forgets that he is an ideological subject.[11,17] This positioning does not allow for a humanized meeting with the user, nor of singular care that favors the creation of bonds.

In our current society, doctors continue to have an instituted *status quo*, that is configured in social relations and power. Their practice is based on the clinical and individualistic model, most of times, with authoritarian positions. However, it is evident that their social place has been gradually modified.[22]

The APS professionals are unable to give resoluteness to the care provided to children/adolescents with chronic diseases. This creates dissatisfaction and disenchantment, which may lead to the breaking of bonds and the removal of the user from the service, who will seek care for their demands in other points of attention.[7] The way the service is organized in the APS also favors the care to the acute conditions.[9] Therefore, it is fundamental to overcome this way of caring, in order to build more stable and lasting bonds with the users, so that strategies are put in place for guiding the users in their path in the healthcare network[7] according to their unique demands.

The discursiveness of the enunciators of this study also shows that the lack of knowledge of health professionals, especially those from the APS, about the aspects of some chronic diseases in childhood and adolescence, as well as their way of caring, delegitimizes their role, while social construction.

The APS professionals are often unprepared regarding their knowledge, skills and attitudes to care for the person with a chronic disease. In addition, there is the perception that the follow-up for chronic diseases is a complex and exclusive competence of the other healthcare network services.[5,9]

When users directly seek specialist care without the APS coordination, there is a loss in the continuity of the care provided and regarding the implementation of the therapeutic plan. It happens due to the lack of effective communication between the APS and the secondary and tertiary points of the healthcare network.[6]

Most of the enunciators of this study - especially the APS professionals - are affiliated with a discourse that is sustained by the emptying, by the erasure of their responsibility for the care of the child and adolescent with a chronic disease. This erasure prevents them from participating in the coordination of the care directed to this population. It is possible to observe here the discursive formation of a work process based on the acute demands, which does not focus on the singularities of the chronic disease, nor on the specificities of the age group for the continuous monitoring that is coordinated by the APS.

The chronic disease of the child/adolescent brings an unpredictability that is common in the routine of the families and even more commonplace when the APS does not take measures to continue offering the care.[26] In addition to providing continuity, the APS must take responsibility for this care and commit to offer the service to this population, the management of these people's care and their economic and sanitary responsibility, which must be intimately known by the health team.[4]

The establishment of bonds and the accountability generated by this may contribute to unique and effective health actions.[21] By coordinating care in the healthcare network, the APS can help ensure that each service sought by the families is a point of the system that provides bonding and accountability. In this way, the possibilities of providing care that favors the adequate management of the disease are extended.

The results of this study show that the care provided to children/adolescents with chronic diseases has been carried out in a fragmented way in the healthcare network, since the bonds are created between the families and the secondary and tertiary points of the healthcare network. Thus, the APS has not been able to fulfill its role as coordinator of the caring process.

It is imperative that a reflection on the work process developed in the services is carried out, and that professionals seek, more and more, to establish care bonds with the families of the child/adolescent with a chronic disease and that further research on the themeis developed, so that the existing gaps in the care provided for chronic diseases in childhood and adolescence are minimized.

CONCLUSION

The DA reference was chosen for this study because it brings the possibility of understanding, through the discursiveness, both the historicity that produces reality, present in the language, and the historical and ideological positioning of the subjects. Through the DA, it was possible to identify the different senses and meanings that involve the creation of bonds between families of children and adolescents with chronic diseases and the services of the healthcare network.

The discursiveness of the enunciators shows that the sense of bond is related to the attention and care offered by the health professionals. The explicit attention and care in the analyzed textual marks is a basic concept, which can be paraphrased in its various senses, such as: accessibility, resoluteness, accountability, humanization, empathy and satisfied expectation. In caring for the other, the individual creates a possible space for creating bonds, which is fundamental for the qualified treatment of chronic diseases in childhood and adolescence, especially to coordinate and guide these families, in order to facilitate their journey through the healthcare network, which is sometimes lonely.

It is necessary that each point of attention of the healthcare network to which the family resorts is a broad, concrete and lasting reference. This should happen especially in the APS, which needs to fulfill its role of care coordinator and be a source of care for this family. Thus, it will be possible to create effective bonds with families and help them cope with the implications of the chronic disease, contributing to the maintenance of the disease control and, consequently, to the reduction of hospitalizations that can be avoided.

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