

Longitudinality and continuity of care for children and adolescents with chronic diseases

Longitudinalidade e continuidade do cuidado à criança e ao adolescente com doença crônica

Longitudinalidad y continuidad del cuidado al niño y adolescente con enfermedad crónica

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ABSTRACT

Objective: To analyze longitudinality and continuity of care provided to children and adolescents with chronic disease, from the family caregiver's perception. **Methods:** This is a qualitative study developed on twelve family members of children and adolescents with chronic diseases, by means of focus groups or semi-structured interviews from February to October 2013, with thematic content analysis. **Results:** Two issues emerged: the constant search and wait for care in the healthcare system and strategies to overcome them; and longitudinality of care: forging a new path. **Conclusion:** Meaningful vulnerabilities are observed regarding the programmatic, institutional and personal levels that leave the children and adolescent vulnerable by lack of adequate monitoring and management of the disease in the health care network. Substantial changes in the ways we organize work and actions in the daily routine of the health services are required to meet the needs of this population.

Keywords: Child's health; Adolescent's health; Chronic disease; Health care.

RESUMO

Objetivo: Analisar a continuidade e a longitudinalidade do cuidado à criança e ao adolescente com doença crônica, na percepção do cuidador familiar. **Métodos:** Pesquisa qualitativa realizada com doze familiares de crianças e de adolescentes com doença crônica, por meio de grupos focais/entrevistas semiestruturadas no período de fevereiro a outubro de 2013 com análise temática de conteúdo. **Resultados:** Emergiram duas categorias temáticas: constante busca e espera pelo cuidado na rede de atenção à saúde e estratégias utilizadas para superá-las; e longitudinalidade do cuidado: caminho a ser construído. **Conclusão:** Observam-se fragilidades expressivas em níveis programático, institucional e pessoal, que deixam a criança e o adolescente com doença crônica vulneráveis pela falta de seguimento e manejo adequado da doença na rede de atenção à saúde. São necessárias mudanças significativas nos modos de organizar o trabalho e as ações no cotidiano dos serviços de saúde para conseguir atender às necessidades dessa população.

Palavras-chave: Saúde da criança; Saúde do adolescente; Doença crônica; Atenção à saúde.

RESUMEN

Objetivo: Analizar la continuidad y a la longitudinalidad de la atención al niño con enfermedad crónica, en la percepción de cuidadores familiares. **Métodos:** Investigación cualitativa cuyos sujetos fueron doce familiares de niños con enfermedad crónica, por medio de grupos focales o entrevistas semi-estructuradas en el periodo de febrero a octubre de 2013, con análisis de contenido temático. **Resultados:** Surgieron dos categorías temáticas: búsqueda constante y espera por el cuidado en la red de atención a la salud y las estrategias usadas para superarlos; longitudinalidad del cuidado: camino a ser construído. **Conclusión:** Se observa fragilidades expresivas en un nivel programático, institucional y personal, dejándolos vulnerables por la falta de seguimiento y la gestión adecuada de la enfermedad en la red de atención a la salud. Son necesarios cambios significativos en las formas de organización del trabajo y en las acciones del cotidiano de los servicios de salud para alcanzar las necesidades de la población en question.

Palabras clave: Salud del niño; Salud del adolescente; Enfermedad crónica; Atención a la salud.

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INTRODUCTION

Chronic diseases are of long or indefinite duration and present uncertain prognoses, characterized by periods of remission and exacerbation of symptoms over time. They require an ongoing care process that does not necessarily result in a cure¹.

In this perspective, longitudinality and continuity of care are understood as essential attributes both to the care provided to children and adolescents with chronic diseases and their families.

Continuity of care in health refers to how users experience the integration of coordination among services, care received during visits to health services over time, and experiences regarding the maintenance of constant, courteous, and coherently articulated care².

Longitudinality - one of the key attributes of the primary health care (PHC) - requires the construction and maintenance of strong relationships between users and health professionals. Thus, with time, it ideally results in mutual cooperation, with users seeking out services independently, regardless of the presence of health problems. This intimate relationship converges with the recognition of the professional and the service as a routine source of care due to the trust established in this relationship³.

In order to ensure these attributes, the Brazilian Healthcare Network (RAS) was constituted to guarantee that users receive the set of actions and services they need with effectiveness and efficiency¹.

The RAS consists of health services characterized by different hard technologies, but with a unified mission, common objectives and cooperative and interdependent actions. Such actions are organized polyhierarchically and coordinated by the PHC system, a point of communication between services, with the aim of sharing responsibilities to provide ongoing and comprehensive care to the population¹.

However, there are gaps in the work process of these health services that are detrimental to the RAS's ability to provide longitudinal and continuous care. These include the non-resolution of demands presented by children with chronic diseases and their families⁴, which can be related to a shortage of professionals who possess the knowledge required for this type of care⁵.

Such lack of resolution begins at the PHC level - the organizing center responsible for coordinating care at different points within the health system - generating dissatisfaction and the non-recognition of PHC as a source of care⁶, which extends to other levels of care. The problems presented by PHC are due to hierarchy- and power-based relationships⁷, weaknesses in logistic and governance systems⁸, and lack of access to and the fragmentation of the system as a whole^{9,10}.

Lack of continuity in care due to the fragmentation of the health care network results in families having to embark on pilgrimages after health care, negatively impacting their quality of life and social vulnerability, in terms of wanting to provide the child with the necessary care and not being able to⁴. A study⁵ conducted in the municipality of Porto Alegre (Rio Grande do

Sul, Brazil) with the aim of gathering data on the perceptions of family members of children with chronic diseases about the components of vulnerability and their relationship with the systems described by Urie Brofenbrenner's socioecological theory, found that the gaps in care provided to the children and adolescents with chronic diseases began at the planning-level of programs and guiding policies for health service networks. These gaps result in situations of programmatic vulnerability, which hinder the organization and quality of services and actions provided, leading to burdens for families and the health system.

Individuals who care for children and adolescents with chronic diseases and who rely on these services experience these problems routinely. Thus, they are particularly qualified to describe the reality of the care context for chronic diseases and contribute so that health care managers and professionals can envisage the necessary changes.

In light of the above, the research question was: how do family members perceive continuity and longitudinally of care provided to children and adolescents with chronic diseases? The objective of this study was to analyze continuity and longitudinality of care provided to children and adolescents with chronic diseases, according to the perception of family caregivers.

METHODS

This was a qualitative study, centered on the social organization of work processes within the RAS related to the provision of health care to children and adolescents with chronic diseases.

The sample comprised 12 family caregivers responsible for children and adolescents with chronic diseases who sought treatment at a public hospital in the state of Paraíba, Brazil, a reference center for this population, between February and October 2013. The following inclusion criteria were used: family members of children or adolescents with chronic diseases; main adult responsible for accompanying child or adolescent throughout the course of the disease; 18 years or older; and the child or adolescent had to have been hospitalized in the pediatric clinic or receiving ambulatory care from the hospital during the period of the data collection. We excluded family members who presented some type of communication difficulty or children and adolescents who had been living with a diagnosis for less than a year.

The healthcare network of the municipality is also a reference center for individuals from other municipalities. Therefore, we included subjects residing in several municipalities of Paraíba.

One researcher was responsible for the data collection process, which took place in the hospital. Initially, the focus group technique was employed. However, the hospital bed turnover rate during the data collection period was not high enough due to the long hospital length of stay of children and adolescents with chronic diseases. This situation led to an insufficient number of participants to carry out focus groups. Furthermore, the technique also proved to be a challenge in the outpatient setting,

as family members were reluctant to leave the waiting room, in fear of missing their appointment. They were also unwilling to stay after their appointment, due to alleged commitments. In light of these challenges, we decided to use individual semi-structured interviews, in order to select new participants and contribute to a more comprehensive analysis of the study.

It is worth mentioning that there were no divergences observed between the data collected by both techniques, whether focus groups or semi-structured interviews, corroborating our inference that the decision to change methodology did not result in biased research results.

One researcher moderated the focus groups, and another functioned as an observer, helping to organize the group and take notes on its dynamics and the singularities presented by participants during interviews. Two focus groups were carried out, with 4 and 5 participants, respectively, with an average duration of 100 minutes; three semi-structured interviews were conducted, approximately 40 minutes each.

Both group and individual interviews took place according to the subjects' availability and were recorded with their consent in order to be fully transcribed at a later moment. The trigger question for both techniques was: "You have children who frequently need assistance from health services. Tell me which health services you have sought out and what each one has done to help you".

All of the transcribed empirical research material composed the textual corpus for analysis, and each individual statement was encoded. Next, the material was submitted to thematic analysis, which focused on the different views presented by the participants to create structures of analysis and empirical categories, in which discourse fragments were organized around the key issues addressed in this study. The first step of thematic analysis was pre-analysis, in which we conducted a fluctuating and thorough reading of the material, providing us with a view of the whole and allowing us to perceive the particularities of the material, organize initial themes for analysis and interpretation, decide on the initial classification and determine the theoretical concepts that would guide the analysis. Next, the data was organized by recording unit and then into themes. The final analysis consisted of grouping such themes by creating thematic categories and then interpreting the final results¹¹. From this analysis, two thematic categories emerged: "the constant search and wait for care in the healthcare system and strategies used to overcome it"; and "longitudinality of care: forging a new path."

The study abided by Resolution no. 466/12 of the Brazilian National Health Council¹² and was approved by a research ethics committee (no. 184.351 and CAAE 11444412.8.0000.5183). All participants signed informed consent forms. To ensure anonymity, focus group participants were identified with the letters "FG" and two numbers - the first identifies the group and the second, the family member (1FG1). The individual interviews are represented by the letter "I", followed by the chronological sequence of the interview (I1, I2, and I3) and any health services mentioned in the interviews were identified with the letters "A", "B", "C", "D" and "E".

RESULTS

Among the family caregivers of children and adolescents with chronic diseases, there were nine mothers, two aunts, and one father. The age group varied between 23 and 45 years old, of which six were married, five single, and one in a stable union. With regard to education level, 7 out of 12 subjects had less than eight years of schooling. Only three participants had formal employment, one was unemployed, and eight were homemakers.

Among the children and adolescents with chronic diseases (Chart 1), six resided in the studied municipality of Paraíba and six in other smaller municipalities in the same state.

The constant search and wait for care in the healthcare system and strategies used to overcome it

The care process for children and adolescents with chronic diseases in the healthcare system presents significant gaps that result in constant pilgrimages by the family:

[...] He left [hospital A] after five days of hospitalization and started getting sick two days after being discharged. I went back to hospital B and they said he had pneumonia [...]. I said that I wouldn't go back there [hospital A] and so I was sent to the other hospital C [...] It was the same thing, there was dirt, seepage [...]. I left with him limp in my arms at 10 PM [...] I went back to hospital B and then it was the first time that I went to hospital D. [...] He had pneumonia again [...] (1FG1)

When hospitalization is necessary, there are entry barriers due to a lack of vacancies:

The hard part is when we have to hospitalize her here [hospital E] [...] Every time we come there are no vacancies (I2)

[...] In an emergency [...] I go to hospital B and it's a waiting game until there is a vacancy. [...] Just the other day I stayed from Saturday, 8 AM, until Sunday with her [the child with a chronic disease] sitting in the chairs [...]. On Sunday, she became sick, I complained and they were able to put her on a stretcher in the observation room. She was on oxygen, on medication until Monday when there was a vacancy and we came here [hospital E]. However, I was the one who made contact with [...] her primary doctor and this vacancy showed up (I3)

In this context, some doctors give their private phone number to some patients, with the intention of helping them get access to healthcare services:

I have the doctor's cellphone number and he says to get in touch with him whenever I need to (1FG4)

Chart 1. Characteristics of children and adolescents with chronic diseases from the participating families in the study. João Pessoa, Brazil, 2013

Chronic disease(s)	Time since diagnosis	Age	Gender	Education Level
(1FG1) Beta Thalassemias; Asthma	1 year	2 years and 3 months	M	-
(1FG2) Coronary Heart Disease; Chronic Kidney Disease	1 year	17 years	F	8 th year of EE*
(1FG3) Laryngomalacia with endotracheal tube	Since birth	1 year and 5 months	M	-
(1FG4) Chronic Liver Disease	1 year	12 years	M	9 th year of EE
(1FG5) HIV Positive	10 years	13 years	F	5 th year of EE
(2FG1) Tay-Sachs Disease	2 years	6 years	M	-
(2FG2) Chronic Kidney Disease	2 years	10 years	M	3 rd year of EE
(2FG3) Liver cirrhosis with transplant in 2010	3 years	11 years	F	4 th year of EE
(2FG4) Congestive Heart Failure; Rheumatic Fever; Cognitive Disability	A long time	15 years	F	6 th year of EE/Is no longer studying
(I1) Cerebral Palsy	Since birth	5 years and 6 months	M	Preschool
(I2) Systemic Lupus Erythematosus; Tuberculosis; Depression	2 years	17 years	F	2 nd year of SE**
(I3) Cystic Fibrosis; Asthma	2 years	5 years	F	Kindergarten

* Elementary Education; ** Secondary Education.

[...] I already know that if she gets a fever, I call him [specialized doctor who is the child's primary doctor] and he already knows where to take her (1FG5)

The lack of coordination between professionals and referral and counter-referral services and the inefficiency of the network regulation system is detrimental to follow-ups, scheduling of procedures, exams and appointments with specialists, and finding vacancies when hospitalization is in order.

It took two months to get it [appointment with a specialist] and even then I went [to hospital E] without a referral (2FG4).

Almost a year went by waiting for an appointment with an orthopedist [...] The neurologist also takes over 6 months. [...] The allergist is quicker. I wait one or two months (E1).

[...] What is tough is this waiting [to schedule appointments] [...]. If I need it [...] they should take advantage of this time that he's here [hospitalized in hospital E] to do the tests [...]. If there are problems with his kidneys that need to be detected in order to know whether or not he needs surgery, why not do it quicker? Why let him suffer, wait until he gets sick again to be able to do it? [...] We don't want to wait to see him suffer or get worse (2FG2).

To minimize the problems due to the fragilities in regulation, some medical specialists, concerned for their patients, schedule return appointments without going through the regulation system. They are able to follow-up with the child or adolescent after hospital discharge.

[...] The appointment is done here [scheduled in hospital E after hospital discharge], they schedule it and I come. (1FG2)

[...] When I come [to the hospital] he [medical specialist] already makes a return appointment, but in case something happens with him [the son] I give him a call (1FG4).

The creation of groups for specific chronic diseases has proven to be an effective strategy that contributes to the quality of care by ensuring continuity. In these groups, family members organize themselves, elect representatives to mediate communication between the specialist teams and group members.

The president of the group gets in contact with [name of medical specialist] and then notifies everyone [when there is an appointment] [...] It also depends on the doctor's schedule [...] Both him and the team come and see us [...] They do the exams, they do everything at the same time (I3).

Longitudinality of care: forging a new path

The Brazilian primary health care system (PHC) has not been able to provide the necessary conditions for the development of longitudinality. This results in caregivers seeking out PHC only for specific reasons, such as, to get referrals to other services or to carry out tests, get medication prescriptions, materials and dental appointments.

[...] We go to PHC for referrals (1FG2).

[...] We only go [to PHC] when we don't have the medication, so the doctor writes a prescription so we can get or buy the medication. [...] or in the case of a basic test or even to see a dentist (I2).

Obstacles to effective longitudinal care are due to gaps in the development of home visits by the team.

[...] I had been living here for three months and the health agent had not shown up [...] My neighbor asked [about the health agent] and [...] said he was going to call the social worker, who came to my house with the health worker. She [social worker] asked the agent why she hadn't visited and she replied that she didn't think anyone lived there [...] The agent asked what material I needed to make the request [...] It's been almost two months and I still haven't seen any material from the health center [...] they don't show up anymore [...] (2FG1)

Another obstacle to maintaining and strengthening relationships with the families is the remapping of health unit territories, which implied a substitution of community health agents.

[...] The health agent still hasn't gone [to make the home visit]. [...] Now the [previous] health agent would visit, ask questions, but the new guy only goes when he has to take a referral (I1).

At my house, she [health agent] still hasn't come [to make the house visit] (I2).

Finally, the families do not feel properly looked after when they need the support of the PHC during care:

He doesn't even get a house visit after returning from hospital E (1FG1).

PHC doesn't follow up. Who does most of the follow-ups here is doctor [name of the medical specialist] on Mondays. I don't think she has anything to do with PHC (2FG3).

[...] I think that they [professionals at PHC] should know a bit more, too [...] I left some pamphlets there explaining

Cystic Fibrosis, to raise awareness [...], but to this day I haven't had any success. And also, I stopped going there [PHC]. I run here [hospital E] for anything [...] (I3).

DISCUSSION

The Brazilian nosological profile requires changes to the current model of health care, as it has not been able to meet the demands of the growing epidemiological profile of chronic diseases. This results in a mismatch between the services provided and actual healthcare needs¹. Corroborating this reality, this study identified weaknesses in the RAS that hamper its effectiveness when providing care to children and adolescents with chronic diseases.

Lack of adequate follow-up with patients in order to conduct early interventions in any clinical alteration is detrimental to disease management. This situation usually leads to caregivers pilgrimaging to several different health services in search of assistance, given that the first service encountered tends to conduct referrals or does not meet their needs^{9,10}.

The Brazilian health system still needs to be adequately organized to respond to the health needs of chronic patients, a reality that burdens health services¹³, a reflection of discontinuity of care. Fragmentation of care occurs due to one-off visits, lack of communication between PHC and secondary care health services and professionals, and lack of coordination between the latter and RAS support and logistic systems⁸. The current mode of organization is still focused primarily on acute conditions, with reactive and episodic responses, resulting in disastrous economic and sanitary consequences over time¹³. In this context, there is no room for constructing permanent partnerships between families and health teams, an essential component of follow-up¹⁴, resulting in constant complaints by caregivers who are continually in line waiting for vacancies at other levels of care.

When constructing care strategies, health professionals must practice empathy in order to recognize the experiences of these families. By placing themselves in another's shoes, professionals are able to reflect on the issue and employ their technical and scientific knowledge to plan more effective strategies that will bring solutions to the problems presented in the arduous pilgrimage described by families¹⁵.

One of the strategies presented in this study was the organization of chronic disease patient groups. With the support of specialized outpatient centers, these groups favored continuity of care. Children and adolescents had easier access to health services and actions when needed, as several resources were made available in the same location.

Another consequence of fragmented care is family caregivers having to face deficiencies in the regulation system, resulting in long periods of waiting for care. This reality can be prejudicial to the child's mental and physical health, causing negative repercussions on their wellbeing and that of their family.

When health needs are readily taken care of, all those involved are benefitted, as indicated by an English study that examined the association between improved chronic disease management by PHC and hospital cost reductions. This study found that, when disease management is in place, individuals with chronic conditions are healthier and develop less complications, thus requiring fewer hospital stays throughout the year and, when needed, with shorter lengths of stay¹⁶.

However, the Brazilian Unified Health System (SUS) is composed of a complex network of public and private services, resulting in the creation of subsystems to meet specific population needs¹⁷. This reality hinders the coordination and continuity of care in the PHC system, generating programmatic vulnerability⁵ in the RAS.

Brazilian PHC must still forge a path toward effective longitudinal care for children and adolescents with chronic diseases. This process requires that the system create means to ensure disease management and provide effective follow-up of individuals with chronic diseases. This form of managing chronic conditions can contribute to improving these patients' quality of life, reduce hospital costs, and promote effective longitudinality of care.

However, as indicated by the study¹⁶, in order for this to occur, some investments must be made in the practical routine of PHC in order to improve disease management, such as improving patient record systems, involving specialized nurses in management, and strengthening the relationship between health teams and the community¹⁶. However, care management can be developed by other professionals with higher education degrees, not only nurses, who are also qualified to play this role, in so far as families have easy access and contact with them. This would strengthen and favor therapeutic and cooperative relationships between both parties.

The quality of the relationship between users and services/professional is essential. However, this requires trust-building interactions, through which caregivers feel looked after and notice the team's interest in their story, demands, and needs⁴.

In contrast with this reality, this study showed the failed attempts of caregivers to mobilize and make PHC professionals take responsibility for the their child's care, resulting in unmet demands. This form of conducting the process generates dissatisfaction and disillusionment, leading to broken relationships and in users distancing themselves from PHC and seeking out other levels of care.

A study conducted in Medellin, Colombia, which investigated how humanized care is understood by those who are directly involved, found that healthcare practices are influenced by three components: first, the social and legislative context; second, regulations that govern health institutions; and third, the relationship established between patients and nurses. The first two define rules for care and the third, the path to its concretion¹⁸.

Thus, the health system is directly influenced by the attitudes and actions of professionals, as these qualify the care provided and are crucial to minimize vulnerabilities experienced by those

involved in the process. From the moment families seek out a particular health service with their children or adolescents, the professionals they encounter become part of their care environment, and they are influenced by how the work is organized⁵.

A study conducted in the municipality of Londrina, Brazil, which compared the organization of PHC actions for users with asthma in services with and without consolidated follow-up programs found that programs with the program displayed more positive results with improved living conditions for users¹⁹. This reality is a reflection of the improved organization of actions and greater adherence of patients to the recommendations provided by the program to prevent new crises.

Family visits represent one of the main strategies that enable longitudinality and continuity of care, as they promote closer relationships³, allowing the team to have a more precise idea of the family dynamics and recognize the family's needs in order to provide effective care.

Parents value the attitude of professionals who show an interest in getting to know their family and children more deeply during home visits. This promotes a relationship based on trust between parents and healthcare professionals², an essential aspect when caring for chronic conditions.

We emphasize the community health agent as a key professional in home visits, working together with the population so that its ties with PHC are maintained. However, home visits conducted both by health agents and other team members display weaknesses, and caregivers do not perceive commitment or concern from the care team, which hinders the identification of these families by the system. Home visit allows PHC health teams to identify families and include them in the registration system²⁰, registering children and adolescents with chronic diseases in order to provide them with follow-up care over time.

However, the results of this study displayed the fragility of the system when searching for and identifying new families in the areas included in the scope of the PHC system. A factor that may have contributed to this gap was the remapping of micro-areas in which community health agents operate, a reality that is counterproductive to the process of strengthening relationships between families and PHC teams.

Notwithstanding, an integrated system must provide notifications when children or adolescents with chronic care are transferred to different coverage areas. In this moment, health information would be shared with the new responsible team, so that they can incorporate such data and guarantee continuity of care. This would promote the formation of bonds between new health teams and families, and consequently, longitudinality, in which PHC is recognized as a legitimate source of care.

Such recognition would also favor the coordination of care, essential to provide qualified follow-up care to children and adolescents with chronic diseases. However, this still represents a challenge for the PHC system²⁰.

While these challenges remain, health care suffers the consequences, with PHC professionals becoming unaccountable for

the effective follow-up of patients and families and the automatic transferal of this role to specialized doctors, who can only be accessed through scheduled appointments. In this context, family members rely on the availability of specialists to follow-up on and take responsibility for their case. This reality leaves children and adolescents with chronic diseases vulnerable to specific and one-off decisions made by doctors, for if they do not intervene and provide them with support, the children will not have timely access to the needed care.

On the other hand, we must recognize that visits with specialists are important and should complement PHC actions, not exempting it from its responsibilities¹⁴. The RAS depends on shared responsibilities in order to function¹, as the lack of collaborative care between PHC and specialists is prejudicial to longitudinality, depriving primary services from its characteristics and essential role in the RAS.

Communication among health professionals is essential to the process of comprehensive and complementary care, in which the actors involved share responsibilities and collaborate with one another. Such communication involves establishing and negotiating actions and responsibilities with the objective of providing safe and effective care¹ and preventing gaps that can interfere in continuity of care.

CONCLUSION

The gaps identified in longitudinality and continuity of care provided to children and adolescents with chronic diseases and their families display the need for significant changes in how health services organize routine work and actions

Health professionals need to overcome the view that associates health services solely with curative actions. To this end, more stable and long-lasting bonds must be established with users in order to institute mechanisms that ensure longitudinality, by constructing lines of care that contemplate disease prevention and health promotion and guide users through the RAS.

Family caregivers are responsible for searching for and choosing health services; however, professionals must be supporting and strive to present solutions to the demands presented. This should be done so as to strengthen the relationship and establish mutual trust.

Caregivers in this study pointed out several weaknesses at the programmatic, institutional and personal levels that interfered with the longitudinality and continuity of care provided to children and adolescents with chronic diseases. These weaknesses result in considerable vulnerabilities to those who experience the entire process inherent to chronic conditions. The existing gaps in the management of these cases result in inadequate and untimely interventions, leading to frequent exacerbations of acute conditions by chronic disease patients.

According to family caregivers, there is no guiding horizon for care practices provided to children and adolescents with chronic conditions. This path must still be forged, beginning with the construction of long-lasting and empathic relationships between professional and caregivers, the basis of any process

that seeks and decisive follow-up to the complexity involved in this type of care.

The present study indicated significant fragilities in the longitudinality of care provided to children and adolescents with chronic diseases. These were due to the lack of responsibility taken by PHC for this population, which is attributed to specialists.

Health actions must be centered on families, and team professionals must develop their work based on proactive and caring actions directed at family members involved with their children's chronic disease. This would help ensure that bonds are strengthened with each encounter in the care process.

The relevance of this study lies in the voice given to users, and its results can contribute to re-thinking the SUS in terms of its network. Further studies involving health professionals and managers must be conducted to investigate the perception of those who provide care and present new reflections that can provide more in-depth knowledge about longitudinality and continuity of care provided to children and adolescents with chronic diseases and their families. Thus, favorable horizons to establish these attributes may be constructed in order to provide this population with quality care.

REFERENCES

1. Brasil. Secretaria de Atenção à Saúde. Departamento de Atenção Básica. Documento de diretrizes para o cuidado das pessoas com doenças crônicas nas Redes de Atenção à Saúde e nas linhas de cuidado prioritárias. Brasília (DF): Ministério da Saúde; 2012.
2. Miller AR, Condin CJ, McKellin WH, Shaw N, Klassen AF, Sheps S. Continuity of care for children with complex chronic health conditions: parents' perspectives. *BioMed Central Health Serv Res*. 2009 dec; 242(9):1-11.
3. Baratiéri T, Mandu ENT, Marcon SS. Longitudinalidade no trabalho do enfermeiro: relatos da experiência profissional. *Rev. Esc. Enferm. USP*. 2012 out; 46(5):1260-7.
4. Costa EAO, Dupas G, Sousa EFR, Wernet M. Doença crônica da criança: necessidades familiares e a relação com a Estratégia Saúde da Família. *Rev Gaúcha Enferm*. 2013 set;34(3):72-8.
5. Pedroso MLR, Motta MGC. Criança e família convivendo com a doença crônica: mesossistema em ligação com a vulnerabilidade programática. *Texto contexto - enferm*. 2013 abr-jun; 22(2):493-9.
6. Nóbrega VM, Damasceno SS, Rodrigues PF, Reichert APS, Collet N. Atenção à criança com doença crônica na Estratégia Saúde da Família. *Cogitare Enferm*. 2013 jan-mar; 18(1):57-63.
7. Macedo LM., Martins STF. Interdependência entre os níveis de atenção do Sistema Único de Saúde (SUS): significado de integralidade apresentado por trabalhadores da Atenção Primária. *Interface(Botucatu)*. 2014 jul; 18(51):647-60.
8. Godoi H, Mello ALSF, Caetano JC. Rede de atenção à saúde bucal: organização em municípios de grande porte de Santa Catarina, Brasil. *Cad Saúde Pública* fev; 2014; 30(2):318-32.
9. Petean E, Araújo LFS, Bellato R, Wunsch CG. Trajetória de busca por cuidado na vivência do evento traumático e sua cronificação. *Saude Soc*. 2013; 22(4):1257-68.
10. Barbiani R, Junges JR, Nora CRD, Asquidamini F. A produção científica sobre acesso no âmbito do Sistema Único de Saúde do Brasil: avanços, limites e desafios. *Saude Soc*. 2014 out-dez; 23(3):855-68.
11. Minayo MCS. O desafio do conhecimento: pesquisa qualitativa em saúde. São Paulo: HUCITEC; 2012.
12. Resolução n. 466, de 12 de dezembro de 2012 (BR). Diretrizes e normas regulamentadoras de pesquisa em seres humanos. *Diário Oficial da União, Brasília (DF): Ministério da Saúde; 2012.*

13. Mendes EV. O cuidado das condições crônicas na atenção primária à saúde: o imperativo da consolidação da estratégia da saúde da família. Brasília (DF): Organização Pan-Americana da Saúde; 2012.
14. Graham RJ. Specialty services for children with special health care needs: supplement not supplant the Medical Home. *Arch Dis Child*. 2008 jan; 93(1):2-4.
15. Fermo VC, Lourençatto GN, Medeiros TS, Anders JC, Souza AIJ. O diagnóstico precoce do câncer infantojuvenil: o caminho percorrido pelas famílias. *Esc. Anna Nery*. 2014 mar; 18(1):54-9.
16. Dusheiko M, Gravelle H, Martin S, Rice N, Smith PC. Does better disease management in primary care reduce hospital costs? Evidence from English primary care. *J Health Econ*. 2011 sep; 30(5):919-32.
17. Paim J, Travassos C, Almeida C, Bahia L, Macinko J. Saúde no Brasil 1: O sistema de saúde brasileiro: história, avanços e desafios. *The Lancet*. 2011 may; 377(9779):11-31.
18. Beltran-Salazar OA. Healthcare institutions do not favor care. Meaning of humanized care for people directly participating in it. *Invest. educ. enferm*. 2014; 32(2):194-205.
19. Carmo TA, Andrade SM, Cerci Neto A. Avaliação de um programa de controle da asma em unidades de saúde da família. *Cad. Saude Publica*. 2011 jan; 27(1):162-72.
20. Figueiredo EN. A Estratégia Saúde da Família na Atenção Básica do SUS. Brasília (DF): UNIFESP/UNA-SUS [on line]; 2012. Disponível em: http://www.unasus.unifesp.br/biblioteca_virtual