

Management of care for children/adolescents with chronic diseases: (dis)articulation of the network and fragmentation of the actions

Gestão do cuidado à criança/adolescente com doença crônica: (des)articulação da rede e fragmentação das ações

Gestión de cuidado de niños y/o adolescentes con enfermedades crónicas: la (des)articulación de la red y la fragmentación de las acciones

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Abstract: Objective: to analyze the management of care for children/adolescents with chronic diseases in the health care network, based on the experiences of families in the search for the care of their child. **Method:** a qualitative research, carried out with ten relatives of children/adolescents with chronic diseases, residents of the city of João Pessoa, Paraíba, Brazil. Data was collected from November 2017 to June 2018 through semi-structured interviews and submitted to inductive thematic analysis. **Results:** the health care network for children/adolescents with chronic diseases is disjointed and the care actions fragmented; families design their own therapeutic itineraries and do not receive support from professionals/services in care management. **Conclusion:** disarticulation in the planning of care actions in health care networks, combined with punctual and discontinuous care for children/adolescents with chronic diseases and their family weaken and impoverish care management.

Descriptors: Comprehensive health care; Child health; Pediatric nursing; Chronic disease; Health management; Pediatric nursing

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Resumo: Objetivo: analisar a gestão do cuidado à criança/adolescente com doença crônica na rede de atenção à saúde, tendo como alicerce as experiências de famílias na busca pelo cuidado do(a) filho(a). **Método:** pesquisa qualitativa, realizada com dez familiares de crianças/adolescentes com doença crônica, residentes do município de João Pessoa, Paraíba, Brasil. Os dados foram coletados de novembro de 2017 a junho de 2018 por meio de entrevistas semiestruturadas e submetidos à análise temática indutiva. **Resultados:** a rede de atenção à saúde de crianças/adolescentes com doença crônica está desarticulada e as ações de cuidado fragmentadas; as famílias traçam seus próprios itinerários terapêuticos e não recebem apoio dos profissionais/serviços no manejo do cuidado. **Conclusão:** a desarticulação no planejamento das ações de cuidado nas redes de atenção à saúde, aliado ao atendimento pontual e descontínuo à criança/adolescente com doença crônica e sua família fragilizam e empobrecem a gestão do cuidado.

Descritores: Assistência integral à saúde; Saúde da criança; Doença crônica; Gestão em saúde; Enfermagem pediátrica

Resumen: Objetivo: analizar la gestión del cuidado de niños y/o adolescentes con enfermedades crónicas en la red atención de la salud, sobre la base de las experiencias de las familias en la búsqueda de atención para sus hijos y/o hijas. **Método:** investigación cualitativa realizada con diez familiares de niños y/o adolescentes con enfermedades crónicas, residentes en el municipio de João Pessoa, Paraíba, Brasil. La recolección de datos se realizó entre noviembre de 2017 y junio de 2018 por medio de entrevistas semiestructuradas, además de ser sometidos a análisis temático inductivo. **Resultados:** la red de atención médica para niños y/o adolescentes con enfermedades crónicas está desarticulada y las acciones de cuidados están fragmentadas; las familias trazan sus propios itinerarios terapéuticos y no reciben apoyo por parte de los profesionales y/o servicios en el manejo de la atención. **Conclusión:** la desarticulación en la planificación de las acciones de cuidado en las redes de atención de la salud, combinada con una atención puntual y discontinua de niños y/o adolescentes con enfermedades crónicas y sus familiares, debilitan y empobrecen la gestión de la atención.

Descriptor: Atención integral de salud; Salud del niño; Enfermedad crónica; Gestión en salud; Enfermería pediátrica

Introduction

In the last decades, advances in health have driven an increasing number of children/adolescents dependent on care and on monitoring and health care. In addition, chronic health conditions in children and adolescents have increased worldwide. A study conducted with families in the United States identified a prevalence of 45% of these conditions.¹ In Brazil, 49.1% of the child hospitalizations are for children with chronic diseases and readmissions for this population reach 50% of the cases.² Thus, in addition to the increase in the number of cases, the vulnerability of this public and the need for effective management of care for the proper management of the situation are evident.

Care management is defined "as the provision or availability of health technologies, according to the unique needs of each person, at different times of their life, aiming at their well-being, security and autonomy to continue with a productive and happy life".^{3:589} It aims to meet such health needs, according to their specificities, articulating them with the individual, family, professional, organizational, systemic and societal dimensions, providing efficient, continuous and comprehensive care.³ These dimensions must be interdependent so that they can meet the specific demands for children/adolescents with chronic disease, favoring continuous and longitudinal care.

From the perspective of nursing, care management is characterized by articulated assistance and management actions between the multidisciplinary team and users.⁴ In the Health Care Network (HCN), this management makes it possible to guarantee integrality and continuity of care.⁵ However, a study⁶ points out that the care management performed by the health services to guide the work of the professionals of the Family Health Units (FHUs) teams in the perspective of comprehensiveness, is still fragile, not considering its dimensions. This generates gaps in the continuity of care, making health care even more fragmented and with little resolution, consequently generating user dissatisfaction. In the case of a chronic condition for children and adolescents, the definition of the diagnosis and the possible prognosis mark the beginning of a new phase for the family, as it begins to adapt the care for the child,⁷ having to (re)organize its functioning in view of the implications triggered by the disease⁸ and the constant search for care in the different health services. In this search for care, the families do not feel supported regarding the service provided by the different points of the HCN, highlighted by a vulnerable and fragmented care, in which, after referral by Primary Health Care (PHC), the individuals start to walk a lonely path from institution to institutions.⁹

In addition, the way in which these networks have been operationalized, have not been effective in meeting the specificities of children with chronic diseases and their families.¹⁰ One of the challenges of this operationalization refers to the organization of the HCN, in which PHC coordinates the care and orders the flow of users, co-responsible with the health providers for planning actions capable of guaranteeing an effective service.¹¹

Although this network is wide and diverse, PHC services, considered the preferred gateway to the health system, show difficulties in accessing them, both in the referral and counter-referral system and in the longitudinality of care, which interfere in solving the health problems of the users.¹² Thus, the families of children with chronic diseases prioritize the search for emergency services, in view of the agility and resolution of their health needs.¹⁰

Another problem refers to the limited planning of care actions for children with chronic diseases. This limitation stems from the fact that the care actions are focused on the disease and on the prescription of treatments, and not on the need to support the parents in their role of managing the care of the child.¹³

Given the fragility of the health actions and services provided to the care demands for children with chronic diseases and their families, the following research question was adopted: How is the management of care for children with chronic diseases taking place in the health care network? Thus, this study aimed to analyze the management of care for children/adolescents with chronic diseases in the health care network, based on the experiences of families in the search for the care of their child.

Method

A qualitative and exploratory-descriptive study, with theoretical support in the concept of care management, conducted in the city of João Pessoa, Paraíba, Brazil. Data collection took place from November 2017 to June 2018, through semi-structured

interviews with ten family members of children/adolescents with chronic diseases. Initially, a Family Health Unit (FHU) from each of the five Sanitary Districts (SDs) of the municipality under study, which constitute the PHC services of HCN, was drawn. The Community Health Agents (CHAs) of these randomly selected teams were contacted to indicate the families of children with chronic diseases registered in the territory, who met the inclusion criteria: being a family member of a child/adolescent diagnosed with a chronic disease; being one of the main responsible people for the care during the course of the disease; being able to understand, express and comprehend the requests for the construction of the research. The exclusion criteria were family members of children/adolescents with chronic diseases who were not at their homes at the time of collection.

At least two draws were carried out by SD for the inclusion of families until reaching the saturation criterion, when it was possible to understand the object of study.¹⁴ However, three families refused to participate, justifying that they had already contributed to other research or that they did not want to talk about the child's case; therefore, additionally, three extra draws were carried out in the districts.

When they identified possible participants, the CHAs mediated the initial contact with the family to inform them about the research and to find out if they were interested in contributing to the study. When they showed interest, the CHA scheduled a day and time with the family caregiver to conduct the interview. A script was used composed of four questions that dealt with the care and monitoring of children in the HCN, and with the treatment and control of their chronic disease. The interviews were conducted by the researcher, in the participants' homes, and were recorded on electronic media after authorization, with a mean duration of 30 minutes.

The collected data were submitted to inductive thematic analysis¹⁵ and developed in six stages, without following a strict order: First, the interviews were transcribed in full,

with re-readings and annotations until they allowed familiarity with the data and the elaboration of codes, based on common characteristics, for similar groups. Then, potential themes were sought from the grouping of relevant data, subsequently reviewed to build the analysis themes, after the refinement of the specifics of the themes. In the last stage, the final report was prepared, after analyzing it in the light of the concept of health care management and the relevant literature.

The research was guided by Resolution 466/12, of the National Health Council with approval by the institution's Research Ethics Committee under Protocol No. 151/1 – 04/27/2017. All the participants signed the Free and Informed Consent Form, confirming their consent. To guarantee confidentiality, the families were coded with the letter “E”, in reference to “*Entrevistado*” (Portuguese for "Interviewee"), followed by the numerical order of the interviews.

Results

Ten primary caregivers of children/adolescents with chronic diseases, nine mothers and a grandmother, aged between 19 and 56 years old, participated in the study; five were married and four had more than eight years of study. The family's monthly income varied from less than one to three minimum wages, with the father being the main provider. Among the children/adolescents of the participating families, the following diagnoses stood out: three with autism spectrum disorders (ASDs) (E1, E2, E4), two with cerebral palsy (E3, E9), one with mental disorder (E5), one with intellectual deficit (E6), one with imperfect osteogenesis (E7), one with heart disease (E8), and one with obesity and mental deficit (E10). Their age varied between 3 and 18 years old, with diagnosis time as follows: less than a year (E6, E9); two years (E8); three years (E2, E3, E5, E7); six years (E1, E4); and 17 years (E10).

The interpretation of the empirical material showed the fragility of the health care actions and organization of the health services of the HCN. Two themes were built from

the results: “(Dis) articulation of the HCN and the solitary construction of the therapeutic itinerary” and “Fragmentation of the actions in the care of children with chronic diseases”.

(Dis) articulation of the HCN and the solitary construction of the therapeutic itinerary

Faced with a disarticulated HCN, the families of children/adolescents with chronic diseases have difficulties in identifying the flows of care. Thus, they carry out exhaustive searches alone in the services of the public health system to bring resolution to the demands in the management of the disease.

You keep circulating [through the health services] not knowing the right place. (E4)

A lot of things I already solved in curiosity, where do I go, what do I do, but guidance, even just going after it. (E6)

The disarticulation among the different services of the HCN makes it difficult for the family to access the care actions that the child with a chronic disease needs. Nevertheless, there is a delay in resolving the child's health demands, impairing the quality of care.

Horrible [referring to the care actions in different health services, repeating the same care actions and without resolving it], because it should have been better, as she's a child, she needs more attention [...]. Everything here is very time consuming, in this SUS [Unified Health System] business. (E8)

Medium [PHC assistance], everything we need we have to suffer to go after it, sometimes the person needs a quick exam and it takes time [in the sense that nothing is done in the same place and all services are distant]. Everything we need [specialized services] we have to go far. (E10)

In addition to the fact that the journey is difficult, exhausting and lonely, the continuity of care for children/adolescents in the HCN can be compromised by the lack of

supplies, the absence and/or constant exchange of professionals, the dissatisfaction of the service, and/or the shortage of specialists for child and youth care. These reflect in the delay in scheduling appointments for the monitoring and follow-up of the cases.

We just go to the doctor, a specialist every hour. What you think is different [child's health problem] is already looking for a doctor [...] there are some professionals who didn't evaluate [...] they don't even help, I changed and changed. (E3)

After you manage [to find a service that takes care of the child], there is still a long time and you have to wait six months to be seen, it's very difficult [...]. It's my daughter, I have to go for it [...]. What is missing? [to improve monitoring] it's the network to have more professionals [...] because the CHA is now absent. Then here it runs out. Sometimes an exam arrives, luckily they always call us to go and get it, but there is no one to deliver it. Not enough personnel. (E4)

[...] it's admitting more professionals [in the specialized services], because they didn't see him there, they had no vacancy and there was no professional. (E5)

I'd like to see more specialists for this [...] sometimes medication is lacking, care takes time. (E8)

It is understood that the disarticulation of the HCN reflects vulnerabilities in the systemic, organizational, and professional dimensions of the care management. This implies the family's lonely and tiring search for therapeutic itineraries that bring resolution to the health demands for children and adolescents with chronic diseases.

Fragmentation of the actions in the care of children with chronic diseases

The families aim for comprehensive assistance and a look towards expanded care, which identifies and meets the needs of the child in addition to the biological condition of

the disease. However, the lack of support to the families by the PHC professionals, the failure to carry out home visits to children in special health conditions and the lack of specialized services close to the residence and linked to the FHTs, impact on the fragmentation of the care actions.

[...] there [FHU] they only have a doctor, a nurse, but I need someone to help me because the person sometimes needs advice, guidance and has no one to guide. (E1)

I think that, they [FHT professionals] need to pay attention to this audience, not only my son, but here there are a lot of special children, visiting the homes, because sometimes what makes visits difficult, is that there is no one to take [referring to a relative] and sometimes, the mothers cannot, I myself because I have another child. (E3)

I think so, it would be good [monitoring by PHC] I don't understand [...] medication stuff, weight [...] I also wanted a psychologist, to talk. (E2)

Close to the home it would be great [specialized service], anything closer, I would go there. If each neighborhood had a specialized unit in their cases [adolescents with chronic diseases], it would be very good. (E10)

Another obstacle resulting from the fragmentation of care actions refers to the lack of information, which distresses and exposes families to situations of vulnerability. The lack of communication among the professionals, health services, and families implies mismatches of information, of diagnoses, and of repeated behaviors in situations of childhood and youth chronic diseases. This gap contributes to the fragmentation of the health actions and, consequently, to the non-longitudinality of care.

I keep flying, so sometimes they [specialists] don't fully explain it to me, I don't know. I only know that this disease, one day can

get better, just say that one day it will get better, but nobody says anything. (E3)

You get there [specialized services], they provide information in half. (E4)

They [specialists] only say that it's incomplete [heart valve problem], but they do not say if they are going to have surgery, if they are going to have a medication, they say nothing. (E8)

Gaps found in the work process of the FHT professionals also contribute to making integrality of care unfeasible. These are due to the weakening of the professional qualification for the care of these children/adolescents.

For the disabled individual? Women if there is [monitoring for the child by the PHC] I don't know, because I don't do it [...]. I think they [FHT professionals] could make a schedule, keep dedicated attention to children with disabilities, I think it's extremely important. (E3)

To be honest, there are some [FHT professionals] who are not good at caring for children, there are some that you see being calm, you can win over the child, but there are others who are not, you should choose another profession. (E4)

First I complain about this orientation at birth, a mother is born unprepared, you don't expect it. You make follow-up, everything, but you don't have that previous diagnosis. When you go [...], then the team, if it is not psychologically prepared to say, explain and guide, this becomes very difficult. I was blowing my mind until the penny dropped. (E6)

He's a special child, everyone knows the rights, but when you get there if there are ten people, you have to wait for the ten to be served. Everywhere there is priority, there [PHC] they don't give priority, we have to wait. (E7)

It is understood that there is no proactivity in the HCN professionals to identify the unique needs of this population and outline a joint therapeutic project, in order to articulate the actions to enhance the care. Thus, the fragmentation of actions and the dissatisfaction of the family with the offered care, resulting from the weakening of care management prevail.

Discussion

It is understood that, when not carried out in the care practice of children/adolescents with chronic diseases and their family, care management fragments the actions of care and (dis)articulates the HCN. Nevertheless, there was lack of knowledge about the flow of care, which leads to an exhaustive and individual search by the families for different health services. Therefore, they build up a solitary walk, in an attempt to solve their children's special health needs.

In the macro-context of care, this difficulty in accessing care actions for services and follow-up is related to the (dis)articulation of the HCN. Therefore, problems are identified in the coordination of care and the shortage of trained health professionals to monitor children/adolescents with chronic diseases and their families.

These gaps in health care for these children/adolescents hamper access to services and better quality of care,¹⁶ resulting in families being overburdened. In addition, they are faced with a disarticulated network and do not find support even after the referral is made, needing to design their own care itinerary.^{7,9}

This occurs when the FHT professionals do not recognize their competence in relation to the coordination of care, in favoring access to health care actions that meet the demands for this population, minimizing the implications arising from chronicity.¹⁷ Among these actions that were not carried out and that weaken the work process in the

PHC, the following stand out: health education, articulation among professionals for planning actions, home visits, and support to families in the flow and counterflow order in the services of the HCN.

Communication problems among the services and even the unpreparedness of the professionals in helping the families, who claim not to carry out the counter-reference, are reflected in a worrying and insecure scenario in the continuity of care,^{12,18-19} highlighting gaps in the professional dimension. These gaps in the professionals' work process result in the weakening of dialog, of direct health care, and/or of the necessary referrals and follow-ups.

Corroborating the findings, a study points out that the difficulties encountered by the women caregivers during the care and monitoring of children with chronic diseases are numerous, and start in the search and confirmation of the child's diagnosis, in which they need to go through several professionals.²⁰ Over time, it is observed that the precariousness of information from the health services, combined with the difficulties of the HCN in monitoring the child/adolescent with chronic diseases, reflects the weaknesses in the professional dimension, generating a lonely walk for the families. In this sense, the support of a duly trained professional who recognizes the organization and flows and counterflows of the HCN is essential, in order to build a therapeutic itinerary to minimize and resolve the inconveniences caused by the disease to the family.²¹

More than resolving the biological problems of their children, the families of children/adolescents with chronic diseases demand care-related meetings. For this, the professional needs to be sensitive and responsive to their expanded demands, seeking a humanized reconstruction of health actions.

In a scenario of accelerated changes in health, a study²² shows that, to help parents deal with the stress associated with chronic diseases in childhood, it is necessary to centralize care in the family, providing assistance for parents' self-care and support for

coping with the situation in the long term. These actions require the establishment of links among families, children/adolescents, professionals, and health services.

The home visit is one of the strategies that could favor the construction and strengthening of the bonds with the PHC; however, it is not being carried out in the practice of these professionals. From the perspective of health promotion, these visits favor support to the families, reducing their burden and facilitating the management of childhood chronic diseases.²³

However, a Canadian study²⁴ analyzing gaps in relation to the professionals and the political challenges for home care of children and adolescents in complex health conditions points out ways to solve them. It proposes better coordination of the services, specific training for the professionals to home monitoring using health care technologies and greater articulation among the services, as well as longitudinal support to the families.

The absence of a broad multi-professional work process, with tools for home care and the scarcity of specialized home care services, highlights vulnerabilities in the organizational and systemic dimension. In this way, care management has a primary role in offering problem-solving services at any level of care and in ensuring trained professionals committed to home care for families of children/adolescents with chronic diseases.

Another way to ensure that this population obtains comprehensive care is through the organization of the various services of the HCN.²⁵ However, the weakened bond with the PHC professionals generates fragmentation of the health actions and obstacles in the dimensions of care management.

The construction of the bond between the health professional and the child/adolescent-family is the result of a relationship of trust, in which the family realizes that their demands are met or even identifies the professional's commitment to the care of their child.⁹ Through the consolidation of the bond, it becomes possible to better adhere to

therapy, and to reduce doubts and family burden. It is perceived that the lack of actions that enable the construction and strengthening of the professional bond between child/adolescent-family hinders the efficiency related to the professional dimension.

The desire to learn to deal with the singularities of children with hemophilia stands out in a study carried out with family members in Sweden. They need the help of the health professionals to provide care with autonomy and independence.²⁴

Longitudinal follow-up can provide actions in which the families feel empowered, supported, and strengthened to seek strategies for daily care and for coping with the adversities of the disease. Thus, it is the professional's duty to carry out expanded health actions, through the empowerment of the families, establishing clear communication and trusting relationships, as well as encouraging the permanence of the parents in the support to self-care.²⁶

The fragility in the bond between the family and the professional has repercussions on the family and individual dimensions, since children/adolescents with chronic diseases have long-term and continuous care needs. For this, an empathic approach is necessary to enable the planning of interventions consistent with their uniqueness, in order to equip families and to ensure that their needs are met at different levels of care.

These families go through specialized outpatient services, hospitals, and rehabilitation centers in the HCN in search of care and monitoring. Thus, they depend on the dimensions of care management to be articulated, favoring and offering care measures and interventions based on their individual requirements in the encounter with the professional.²⁷

The low resolution of the PHC and the offer of singular care actions show weaknesses in the systemic and professional dimensions of care management for children with chronic diseases and their families. In the systemic dimension, the need to build connections among the health services is identified, shaping care networks and lines,

mainly due to the scarcity of information about which services individuals should seek to continue the care and follow-up of the disease.

It is recognized that the coordination of this care requires the involvement and co-responsibility of the health professionals, through the planning of efficient actions for qualified care. However, the lack of specialized professionals to deal with children with chronic diseases can also cause harms to the quality of care due to the scarcity of specific care strategies for these individuals.¹⁰

The lack of comprehensive care that also includes the provision of psychological support for the child/adolescent with a chronic disease and their family causes dissatisfaction with the care offered and the constant exchange of health professionals and services. In addition, the small number of professionals, especially those trained to deal with the specific needs of these people, hinders the provision of the service and generates dissatisfaction with the provided care. Gaps in care management are evident in ensuring support and efficient care for these families in managing childhood and youth chronic diseases.

The provision of comprehensive care is also rendered unfeasible due to the low resolution of the HCN by the fragmentation of actions, making it unable to meet health demands.²⁸ Allied to this, the ignorance of the services about the flow of patients inside the HCN causes losses in the referral and counter-referral system.²⁹

In view of the care and monitoring needs of their children, the families look for services/professionals that have a humanized look at issues related to the chronicity condition. In addition, they crave for empathetic support from the professionals to resolve their doubts and to monitor the chronic disease.

In order to overcome the weaknesses in the HCN macro-context, the State, on behalf of the corporate dimension, needs to know this population and its singularities in order to develop and implement appropriate policies in the management of childhood and youth

chronic diseases. Corroborating this aspect, a study showed gaps in the societal dimension, due to the lack of knowledge of the State about the demands for the chronic disease and, sometimes, the lack of knowledge of the population profile, which do not allow contemplating the specificities of the child/adolescent with a chronic disease in action planning.²⁵

Therefore, it is essential that the HCN implements actions that strengthen the system and allow individuals to have a successful experience in accessing the services and ensuring continuity of care.¹¹ Thus, the results of this research may come to sensitize managers and health professionals to the construction and implementation of public policies and new strategies meeting the needs of children with chronic diseases and their families. Furthermore, it suggests that the scientific society uses these results for developing studies that train the health professionals on such problems.

The limitations of this study are related to the fact that it was carried out in just one municipality, which possibly makes generalizations impossible. Moreover, there was difficulty in accessing the families of children/adolescents with chronic diseases due to the lack of knowledge of the FHTs about the existence of this public in their assigned area, as well as the obstacles to getting to the homes in the company of the CHAs.

Conclusion

With regard to the work process of the health professionals, especially nursing care for children/adolescents with chronic diseases and their families, gaps were identified in the multiple dimensions of care management in meeting the unique needs of this population throughout the HCN. This fact contributes substantially to the disarticulation of the HCN and to the solitary construction of the therapeutic itinerary by the family members. However, it also causes fragmentation of the care actions due to the lack of communication among the professionals, health services and families, resulting in

localized and discontinuous services. Thus, it is impossible to provide comprehensive care to children/adolescents with chronic diseases and their families. Based on these findings, nursing may come to promote advances in care for this population, by reflecting on their work process in finding new horizons for their care practice.

Thus, the need for training the HCN professionals and for conducting new research studies for the elaboration and implementation of more effective strategies in the referral and counter-referral system is evident. From this perspective, it is necessary to improve communication among health professionals/services/families at different care levels, with a view to improving the articulation among the dimensions of care management.

Further research studies are recommended, focusing on the family support strategies. It is also necessary to instruct the FHTs in relation to the multiple dimensions of care management and its constituent elements to rethink/reconstruct their work process from the perspective of integrality and longitudinality.

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