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Actions of the expanded family health center in care for children and adolescents with chronic disease

Ações do núcleo ampliado de saúde da família no cuidado infantojuvenil com doença crônica

Acciones del núcleo ampliado de salud de la familia en la atención de niños y adolescentes con enfermedades crónicas

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ABSTRACT

Objective: to describe the care provided by personnel of Expanded Family Health and Primary Care Centers for children and adolescents with chronic disease, and their families. **Method:** in this qualitative, exploratory-descriptive study with ten professionals of an Expanded Family Health and Primary Care Center in a state capital in northeast Brazil, semi-structured interviews were conducted between November 2016 and June 2017, and the resulting data were interpreted in the light of inductive thematic analysis. **Results:** consultations, home visits, health education and personalized therapeutic projects were found to contribute to health care. Nevertheless, these measures are still weak and ad hoc, which impairs the service's effectiveness. **Conclusion:** the actions taken by these professionals were only incipient and highlighted gaps in care that undermined continuous, longitudinal monitoring of this public.
Descriptors: Child; Adolescent; Chronic Disease; Patient Care Team.

RESUMO

Objetivo: explicitar as ações de cuidado desenvolvidas pelos profissionais do Núcleo Ampliado de Saúde da Família e Atenção Básica a crianças/adolescentes com doença crônica e suas famílias. **Método**: estudo qualitativo, exploratório-descritivo, realizado com dez profissionais do Núcleo Ampliado de Saúde da Família e Atenção Básica, de uma capital do nordeste, entre novembro-2016 e junho-2017. Utilizou-se a entrevista semiestruturada e os dados foram interpretados à luz da análise temática indutiva. **Resultados**: evidenciou-se que a interconsulta, as visitas domiciliares, a educação em saúde e o projeto terapêutico singular contribuem para o cuidado em saúde. Contudo, ainda são ações frágeis e pontuais, comprometendo a resolutividade do atendimento. **Conclusão**: as ações realizadas por estes profissionais têm sido incipientes e indicam lacunas no cuidado que comprometem o acompanhamento longitudinal e contínuo a este público.
Descritores: Criança; Adolescente; Doença Crônica; Equipe Multiprofissional.

RESUMEN

Objetivo: explicar las acciones de atención puestas a cabo por los profesionales del Núcleo Ampliado de Salud de la Familia y Atención Primaria para niños/adolescentes con enfermedades crónicas y sus familias. **Método:** estudio cualitativo, exploratorio-descriptivo, realizado junto a diez profesionales del Núcleo Ampliado de Salud de la Familia y Atención Primaria, en una capital del noreste de Brasil, entre noviembre de 2016 y junio de 2017. Se utilizó la entrevista semiestructurada y los datos se interpretaron a la luz del análisis temático inductivo. **Resultados:** se notó que la interconsulta, las visitas domiciliarias, la educación en salud y el proyecto terapéutico singular contribuyen a la atención de la salud. Sin embargo, estas acciones siguen siendo frágiles y puntuales, comprometiendo la capacidad resolutiva de la atención. **Conclusión:** las acciones realizadas por estos profesionales han sido incipientes y muestran brechas en la atención que comprometen el seguimiento longitudinal y continuo de este público.
Descriptores: Niño; Adolescente; Enfermedad Crónica; Grupo de Atención al Paciente.

INTRODUCTION

Changes in the global epidemiological scenario point to the increase in the number of children/adolescents with chronic diseases[1,2]. In Brazil, it is estimated that 29.8% of the child-youth population is affected by chronic conditions, representing an increasing and alarming fact[3].

These conditions, of an uncertain and limiting nature, can present remission and intensification periods, requiring continuous care in the health services[3], which also require modifications and incorporation of routines into the everyday practices[4,5]. Thus, they represent a challenge for these services, as chronicity generates the need for effective management of the care networks[5,6], with resolute and comprehensive care, to improve quality of life and minimize complications of the disease. Therefore, there must be care coordination by the Primary Health Care (PHC) team with longitudinal support of the other services belonging to the Health Care Network (*Rede de Atenção à Saúde*, RAS)[3].

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Despite the difficulties, it is indispensable to identify strategies to articulate the work of different professionals in monitoring children/adolescents with chronic diseases[7]. Such articulation can be carried out by the Family Health Teams (FHTs) with the members of the Family Health Support Center (*Núcleo de Apoio à Saúde da Família*, NASF) and the different child/adolescent care services. This enables access to information, shared appointments between the professionals and better team performance for care continuity[8].

The NASF was instituted by Ordinance No. 154/2008 and was given the name of Family Health and Primary Care Expanded Center (*Núcleo Ampliado de Saúde da Família e Atenção Básica*, NASF-AB) by Ordinance No. 2,436 in 2017. It consists of a multiprofessional and interdisciplinary team, complementary to the FHTs. Their work process, guided by matrix support, must focus on the health demands of the individuals in the territories in which they work, being responsible for actions to face the difficulties of PHC professionals[9].

After the implementation of the new National Primary Care Policy, maintenance of the NASF-AB by the municipalities became optional and accreditation of new teams was prohibited, generating uncertainties as to its continuity, despite the importance of its action plan.

Given this reformulation, the multiprofessional teams ceased to be linked to the NASF-AB typologies[9], decharacterizing the scope of the support actions. Therefore, it is necessary to pay attention to these changes and to the impact on the complementarity of the FHTs' work performed by the NASF-AB.

Given the need for continuous monitoring by the health services for the proper management of children's chronic diseases and for the reduction of unnecessary hospitalizations, the importance of support from the NASF-AB in the development of care management actions, whether care and/or educational actions, is highlighted[9], for an effective follow-up of of this population by the FHT.

However, the NASF-AB work process also prioritizes the managerial activities that hinder implementation of its real duties, intervention practices and support functions[9]. In addition, there is a deficit in the flow organization for referrals in PHC, including those directed to the NASF-AB[10], generating gaps in the line of care and in the articulation of the multiprofessional team focused on this population.

Given the above, the following question arose: How do the NASF-AB professionals work in the care provided to children/adolescents with chronic diseases and their family members? Therefore, the objective was to explain the care actions developed by the NASF-AB professionals in relation to children/adolescents with chronic diseases and their family members.

METHOD

A descriptive-exploratory and qualitative study based on the recommendations set forth in the Consolidated Criteria for Reporting Qualitative Research (COREQ).

The study participants were ten NASF-AB professionals, working in ten Family Health Strategy (FHS) units from a Brazilian northeastern capital city. Of the 191 FHS units, two were randomly selected per health district, among the five that comprise the Primary Health Care network.

The inclusion criteria were as follows: being a health professional who cares for children/adolescents diagnosed with chronic diseases in the FHS; and working at the NASF-AB for more than six months, as it was possible to experience care for these individuals and their families. Four professionals were excluded, for being distanced from work during data collection due to holidays, leave and certified medical reasons. It is noted that no professional refused to participate in this study.

The data were collected between November 2017 and June 2017 by only one researcher, an undergraduate student trained through activities in a research group. Individual semi-structured interviews were conducted, guided by the following questions: Which are the characteristics of the monitoring offered by the NASF-AB to children/adolescents with chronic diseases? How important is the NASF-AB team in this monitoring? What actions does the NASF-AB perform in the care provided to this population?

To such end, previous in-person contacts were established with the participants to explain the research and obtain the due consents. Subsequently, the interviews were conducted in a private space at the FHS units, with the sole presence of the interviewer and the interviewee. They lasted a mean of 40 minutes, recorded in digital media and transcribed in full for analysis. Closure of this stage followed the saturation criterion, when it was determined that it was possible to verify the data internal logic in order to understand the study object[11].

The data were submitted to Inductive Thematic Analysis (ITA) to assess the topics (patterns) capable of enabling understanding of the phenomena under study. Six phases were followed for this purpose, namely: familiarization with the topic - transcription and repeated readings of the dataset; initial coding - identification and grouping by similarities; search by topics - selection of different codes in potential topics; review of the topics - refinement of the topics; definition and naming of the topics; and elaboration of the final report[12].

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The study was approved by the Ethics Committee and all the participants signed the Free and Informed Consent Form, as well as had their anonymity guaranteed by using the initials of the professional category, followed by the ordinal number of the sequence in which the interviews were conducted.

RESULTS

Three social workers (SW), two physiotherapists (PT), two nutritionists (Nu), one psychologist (Ps), one speech therapist (ST) and and one physical education professional (PhEP) participated in this study; among them, five have a *lato sensu* graduate degree in different fields. All were temporarily hired by the Municipal Health Secretariat, and had been working in the NASF-AF from one to five years

Two topics were elaborated from the ITA: "Care actions developed by the NASF-AB team in relation to children/adolescents with chronic diseases and their family members" and "Weaknesses in the care actions developed by the NASF-AB team in relation to children/adolescents with chronic diseases and their families".

Care actions developed by the NASF-AB team in relation to children/adolescents with chronic diseases and their family members

The interconsultations for children/adolescents with chronic diseases and their families represent one of the NASF-AB actions.

> *The NASF receives interconsultations involving the physician, social worker and physiotherapist and makes the visit in an integrated manner, each one covering their field and performing their procedure on that day. (SW3)*
>
> *There's knowledge exchange during the interconsultations. [...] in the shared appointment, we come to some common denominator. (PT7)*

The importance of the home visits is emphasized because they enable contact with and recognition of the families' contexts.

> *Home visits are extremely valuable, the homes talk to the professional, then, they notice several issues that involve the context of this family, which sometimes are not evidenced in the unit. [...] Most (of the families) feel welcomed. (SW2)*

The home visits can be uniprofessional or multiprofessional, depending on the care demand.

> *It will depend on the context. [...] Through monitoring and guidelines, such as two, three or even more sessions to solve the problem and [...] schedule continued care for this child/adolescent. (PT4)*

The NASF-AB and FHS actions seek to produce expanded care and are fundamental to adequately manage the disease.

> *Each professional [...] contributes to health care, as human beings are complete. [...] This expanded perspective gives hope to the families. (SW3)*
>
> *From the moment that, as professionals, we work as a multiprofessional team, my knowledge expands [...] it adds to the child/adolescent and their family, making care more complete. (Nu8)*

The NASF-AB professionals mobilize the FHT to work in the therapeutic project according to the specific demands of this population.

> *Based on the needs presented by the user, we indicate which professionals will assist this population at their homes. (PhEP5)*
>
> *Depending on the child's condition, the NASF team performs the monitoring. (Nu8)*

The Singular Therapeutic Project (STP) is pointed out as a comprehensive care action, as it contributes in the NASF-AB actions for this population.

> *The STP promotes continued care for the child/adolescent. It's a process that benefits the child/adolescent, the family and the team. [...] This promotes learning for the NASF and for the FHT. (PT4)*
>
> *The STP is extremely important to understand all the aspects that involve that child, in addition to generating better resoluteness [...] generally, the NASF, the health unit and the family are involved. (ST10)*

The NASF-AB team instructs the families to participate in the care provided to these children/adolescents. Thus, they believe that they contribute to improving their quality of life.

> *Guide the family to be participative [...] contributing during the healing process of that child/adolescent, or else for better quality of life. (PT4)*
>
> *He (NASF-AB professional) [...] instructs the families about the best way for them to deal with the child's problem. (PT7)*

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The NASF-AB social service takes on the role of demystifying biologicist care, as well as of sensitizing the family members to seek PHC more.

> *One of the challenges of the social service is to sensitize these users to go to the unit [...] look for information, and leave with an exchange of experiences. (SW2)*

The NASF-AB care actions can rely on the support of the Home Care Service (*Serviço de Atenção Domiciliar*, SAD), meeting the families' specific demands.

> *Depending on the need, we can activate the SAD services [...] for them to evaluate and carry out the procedure. (PT4)*

The care record on the medical chart of children/adolescents with chronic diseases made by the professionals contributes for longitudinal follow-up.

> *There is a medical chart, and everything that is done is recorded there [...]. This allows us to perform adequate monitoring. (PhEP5)*
>
> *When there is this feedback, monitoring is carried out in the medical record in relation to what they are doing in another service and we also record in it everything we are doing. (ST10)*

Establishing links facilitates the actions developed, as it allows the care plan to occur in an expanded, continuous and resolute way.

> *I try to establish the best link possible with the health agents to know how the child is. [...] I also try to have a strong bond with the family, to offer them sound guidelines. (Nu1)*
>
> *When the link actually exists, we are able to work beyond the complaint. (SW2)*

Weaknesses in the care actions developed by the NASF-AB team in relation to children/adolescents with chronic diseases and their families

Although the participants have addressed follow-up of these children/adolescents, a deficit in the continuity of the care provided to this population was evidenced. This happens because the actions performed are limited to identifying health needs, carrying out home visits and referrals to reference services, without, however, explaining the follow-up after the referral.

> *We carry out the monitoring in one or two visits and make the due referrals. The NASF does not provide care, it doesn't treat the disease [...] (SW3)*
>
> *The NASF works directly articulating the network with the other services. [...] Through the regulation, we schedule the appointment, the exam. (PhEP5)*

Although the relevance of the guidelines for the care and active participation of the family in the daily life of this population is highlighted, the actions of each professional are restricted to their field, contradicting what was explained above.

> *Each professional, within their specialty, identifies the contribution they can offer. (PhEP5)*
>
> *The speech therapist will identify possible changes, both in language, hearing, food, if there is any change in order to improve these children/adolescents' quality of life and guide the families. (ST10)*

Actions for the prevention of possible complications of the chronic disease were pointed out as duties of the NASF-AB; especially education in health, which, despite having been implemented, does not address the specificities of this population.

> *The NASF work is all about prevention. We don't want the children with chronic diseases to get worse. (Ps6)*
>
> *We created a waiting room, covering everyone present, from children to older adults, it is more from a maximizing perspective, it is not specifically aimed at children/adolescents. (SW9)*

Although the group activities are considered important for specific care, they fail to include children/adolescents with chronic diseases.

It's the groups that allow for knowledge exchange, not the appointments. (SW2)

> *Something that would work well is the groups [...]. Perhaps it was the case to have one directed to these children. (Ps6)*

Regarding the care for child-youth diseases, the NASF-AB professionals are unaware of its performance.

> *It is necessary that the NASF deepens on the needs of these children/adolescents, for not knowing very well their demands or how to act. (Nu1)*

Managerial support to the FHS team stands out as a duty of the NASF-AB. This action contributes in the FHS work process, although it has been weakening the care actions performed by the NASF-AB professionals.

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Primary care has several forms for the professional to fill out, bureaucracy is huge, [...] it hinders our work. (SW2)

Many times, we get stuck with the unit's bureaucratic issues and this care part is almost forgotten. (PT7)

DISCUSSION

Articulation of the collective work can expand the possibilities regarding actions and understanding of the role of each professional in the team and in the health system. In this sense, it is sought to break with care fragmentation, with care integrality as a goal[13].

Interconsultation was considered by the participants as an important tool in the care of children/adolescents with chronic diseases, aimed at understanding their needs, through the integration of knowledge from different professional categories.

It was also evidenced that the individuals' contexts exert an influence on their health status. Thus, home visits are an efficient care strategy, as they provide knowledge of the situation experienced at the homes, strengthening the bond between NASF-AB professionals and users. A study corroborates this finding highlighting the importance of the actions developed by the NASF-AB together with the FHTs, including the conduction of group activities, workshops and home visits. Home visits are a light relational technology, based on daily demands of the territory, the community and the health team[14], who try, *in loco*, to identify problems and seek solutions based on the family context. It emerges as a powerful technical-assistance and pedagogical strategy in health care, with positive effects on the users' follow-up[15].

Although the everyday practices are not driven by teamwork, nuances of this *modus operandi* were evidenced, as actions seeking comprehensiveness through different views to meet the singularities of those who experience chronic conditions, even though they lack foundations to become a way of organizing work.

Integrality enables a reflection on the care practices, having to be widely discussed in the everyday practice of the service for its absence to be perceived[14]. The NASF-AB and FHS professionals must cooperate and interact in order to ensure user-centered assistance[11].

Care practices focused on integrality require, minimally, multiprofessional and interdisciplinary articulations to enable expanded care. It is noteworthy that, to achieve this care, the actions developed by the NASF-AB together with the FHT need to be guided by shared care, with interdisciplinary intervention, knowledge exchange, mutual accountability and common actions in the territories under their responsibility[14].

Then, the STP is seen as a set of therapeutic courses of action proposed that ensure this comprehensive care to the individuals. There is appreciation of singularity in its elaboration, highlighting the social dimension implicit in it. However, this instrument is still subjected to resistance in acceptance and use by most of these professionals, as it is understood as incipient and still little known by them[11]. Nevertheless, it is reiterated that elaboration of the STP contributes to singular care in each phase of chronic diseases.

As co-participants in care, families need to be included in the development of an action plan focused on the patients' demands from the beginning, so that they feel engaged and co-accountable for the care provided, especially in the home environment. The practical support offered by the professionals to help deal with chronicity[16,17] is one of the ways to promote family autonomy in the care process, with co-accountability as a horizon.

On the other hand, when there is a gap between health professionals and families, bonding is compromised, as well as care continuity and coordination, essential components for care quality[18]. In this context, the importance of the NASF-AB professionals sensitizing the families of children/adolescents with chronic diseases is highlighted, so that they do not disconnect from PHC, the primary locus for health care follow-up. In the absence of a bond with PHC, the specialized services become periodic sources of care. This is due to the greater involvement and contact of the professionals working in these services with the users[7].

In addition, it was evidenced that the families seek support in other RAS services, such as the SAD, wishing for resoluteness for the children's demands. However, this path can lead to an endless pilgrimage when care is not coordinated. It becomes necessary to reorganize the practices and service offers so that the RAS meets the demands of the population covered[5].

There is appreciation of the recording of the monitoring carried out in an articulated and shared manner by the NASF-AB and by the other professionals from other health services. This practice favors co-accountability for the care between the services, professionals and users, providing care longitudinality. In opposition to these

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results, a study identified that FHTs attribute little importance to the users' medical charts and their records, sometimes exposing the families to stressful situations and launching them into an unnecessary pilgrimage through the network[19].

Nevertheless, strong bonds between the team and the family favor knowledge of the users' needs, as trust in the relationship opens up space for the exchange of knowledge and experiences. This way of producing care is linked to a holistic perspective, which goes beyond the complaint-course of action model.

It is noted that an affective and differentiated professional-family-child bond promotes security, self-confidence and trust in the others, as well as better coping with the disease[19]. However, the temporary hiring of the NASF-AB team makes it difficult to establish a bond between the professionals and the population,[13] which needs to be rethought by the health managers.

The participants of this study highlighted that home health care aims at understanding the socioeconomic and cultural contexts of this population. This assertion is in line with longitudinal care, although contradictions in its operationalization were evidenced, as the *modus operandi* centers the actions on the professional training area, hindering apprehension of the whole. When monitoring only focuses on specific training, it generates care fragmentation.

The training of health professionals persists in a technical and healing care model. Thus, development of the capacity for an expanded approach to the demands of these individuals takes place through the incorporation of new practices and knowledge acquired during work experiences at the NASF[17].

The RAS, especially PHC, must be articulated and prepared to meet the needs of children/adolescents with chronic diseases and their families. In addition to developing strategies to improve quality of life, it is indispensable that the professionals are trained to resolutely respond to the demands imposed by chronic conditions[7].

However, many professionals still focus their actions on the implementation of techniques, seeking to attain only practical success in the care based on the biologicist model[17]. For such reason, comprehensive care is weakened by the deficit in the elaboration of joint actions between the caregivers of this population and the professionals. The construction of bridges for the articulation of work across different professionals and services can contribute so that, progressively, the specific knowledge centers enrich the common field of competences, expanding the care capacity of the entire team[11].

The prevention actions were praised by the NASF-AB professionals, but they do not take into account the uniqueness of these children/adolescents, whose prevention focus should be the reduction and intensification of health problems. When silencing this aspect, the professionals' lack of knowledge about some child-youth chronic diseases and their implications is evidenced.

The professionals are unaware of which their course of action should be in the care of child-youth chronic diseases. Therefore, the training process must overcome the current health care model, prioritizing comprehensive care in all health conditions[19]. Thus, it is indispensable that the professionals take advantage of all contact opportunities with the child/adolescent and their family member/caregiver to prevent comorbidities and promote health[18].

The fact the the NASF-AB professionals are assuming bureaucratic actions in the unit, to the detriment of their care functions, is added to the aforementioned aspects. It is noteworthy that, when developing part of their work process in the units' managerial aspect, they imprison the NASF-AB in technical-managerial activities, limiting its work in care[20].

FINAL CONSIDERATIONS

This study explained the actions developed by the NASF-AB with children/adolescents with chronic diseases and their families, enabling the identification of gaps in care and supporting the implementation of practices aimed at this population. Interconsultations, home visits, referrals to reference services, education in health and the STP were health actions performed by the NASF-AB that contribute to the care provided to this population. However, some of them are still weak, impairing care resoluteness and comprehensive health care.

Although the study was limited to a single municipality, it contributes relevant findings to rethink the NASF-AB actions in the necessary articulation for the care of children and adolescents with chronic diseases. The NASF-AB actions are focused on the biologicist model; therefore, it is urgent to overcome this paradigm and advance in care with a focus on the singularities of this population, encouraging them to become co-responsible for their care process.

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