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SUPPORTED SELF-CARE ACTIONS FOR CHILDREN AND TEENAGERS WITH CHRONIC DISEASES

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ABSTRACT

Objective: to analyze actions of Primary Health Care teams from the perspective of supported self-care for children and adolescents with chronic diseases.
Method: a qualitative study, conducted between April and August 2016, with 11 primary care professionals from a municipality of Paraíba, Brazil. A semi-structured interview supported data collection; and a thematic analysis backed interpretation, which categorized the actions according to the 5 A´s methodology (Evaluation, Guidance, Agreement, Assistance, Follow-up).
Results: there were insufficient actions in the specific care plans. Isolated interventions are performed including: assessment of barriers to self-care and emotional state of the individual; provision of information on signs, symptoms of disease and treatment; stimulating the search for community resources; actions inherent to professional training; and follow-up by active search and home visits.
Conclusions: actions in Primary Health Care do not yet value the active and co-responsible role of the individual in the control of their disease, with gaps to be overcome in the five pillars of supported self-care. Intervention studies are recommended that train professionals regarding supported self-care of these individuals.

DESCRIPTORS: Child. Adolescent. Family. Chronic disease. Self care. Primary health care.

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AÇÕES DE AUTOCUIDADO APOIADO A CRIANÇAS E ADOLESCENTES COM DOENÇAS CRÔNICAS

RESUMO

Objetivo: analisar ações das equipes da Atenção Primária à Saúde na perspectiva do autocuidado apoiado de crianças e adolescentes com doenças crônicas.
Método: estudo qualitativo, realizado de abril a agosto de 2016, com 11 trabalhadores da atenção primária de um município da Paraíba, Brasil. A entrevista semiestruturada subsidiou a coleta de dados; e a análise temática balizou a interpretação, que categorizou as ações conforme a metodologia dos 5 As (Avaliação, Aconselhamento, Acordo, Assistência, Acompanhamento).
Resultados: evidenciaram-se ações insuficientes no plano de cuidados específicos. São realizadas intervenções isoladas incluindo: avaliação de barreiras para o autocuidado e do estado emocional do indivíduo; fornecimento de informações sobre sinais, sintomas da doença e tratamento; estímulo da busca por recursos da comunidade; ações inerentes à formação profissional; e acompanhamento, por meio da busca ativa e visitas domiciliares.
Conclusão: as ações na Atenção Primária à Saúde ainda não valorizam o papel ativo e corresponsável do indivíduo no controle de sua doença, havendo lacunas a serem superadas nos cinco pilares do autocuidado apoiado. Sugerem-se pesquisas de intervenção que capacitem os trabalhadores para o autocuidado apoiado à saúde desses indivíduos.

DESCRITORES: Criança. Adolescente. Família. Doença crônica. Autocuidado. Atenção primária à saúde.

ACCIONES DE CUIDADO PERSONAL QUE APOYAN A NIÑOS Y ADOLESCENTES CON ENFERMEDADES CRÓNICAS

RESUMEN

Objetivo: analizar las acciones de los equipos de la Atención Primaria de la Salud desde la perspectiva del autocuidado, apoyado por niños y adolescentes con enfermedades crónicas.
Método: estudio cualitativo, realizado de abril a agosto de 2016, con 11 trabajadores de la red de servicios básicos de un municipio de Paraíba, Brasil. Una entrevista semiestructurada subsidió la recopilación de datos; Un análisis temático apoyó la interpretación, que clasificó las acciones según la metodología de los 5 Aes en portugués (Avaliação, Aconselhamento, Acordo, Assistência, Acompanhamento): Evaluación, Asesoramiento, Acuerdo, Asistencia, Seguimiento.
Resultados: se pudo evidenciar insuficientes acciones en el plano de los cuidados específicos. Se realizan intervenciones aisladas, que incluyen: evaluación de barreras o autocuidado en el estado emocional del individuo; información para signos, síntomas de enfermedad y tratamiento; el estímulo busca recursos de la comunidad; acciones inherentes a la formación profesional; y seguimiento en busca de visitas activas y domiciliarias.
Conclusion: las acciones en la Atención Primaria de la Salud aún no valoran el papel activo y corresponsable del individuo en el control de su enfermedad, con brechas que deben superarse en los cinco pilares del autocuidado apoyado. Se sugieren investigaciones de intervención que permitan a los trabajadores apoyar el autocuidado para la salud de estas personas.

DESCRIPTORES: Niños. Adolescente. Familia. Enfermedad crónica. Autocuidado. Atención primaria de la salud.

INTRODUCTION

Supported self-care actions aim to empower people with chronic conditions and their families by helping them understand their central role in managing the disease, make informed care decisions and engage in healthy behaviors.[1] This methodology is developed through the 5 A´s strategy (Evaluation, Guidance, Agreement, Assistance and Follow-up), in which the health professional values the realization of health actions, relating these five pillars to the ordering of health care.[2]

Chronic diseases have been expanding worldwide, including in Brazil, whose National Household Sample Survey, studied 12 chronic health diseases which were identified in 9.1% of children aged between 0-5; 9.7% between 6 - 13 and 11% between 14 - 19 year olds of the general population in this age group.[3]

Due to this increase, it is necessary to prepare health professionals to provide continuous care to children/adolescents with chronic diseases, in order to prevent complications resulting from the lack of adequate monitoring.[3] From this perspective, it is understood that these professionals have an important role in fostering the development of self-confidence and self-care[4–5] in these children/ adolescents, as well as family members, since, depending on the age, the child will present certain difficulties inherent in the growth and development process that influence the management of the disease.[6]

As a result of maturity, some children do not understand what professionals tell them and do not directly participate in decisions about their care, while adolescents tend to be influenced by peers and the media.[7] Thus, a collaborative relationship between them, health professionals and their families helps these individuals to make good choices and maintain healthy behaviors.

However, many children and adolescents with chronic diseases require complex home care, most often without the necessary support from health professional management; and even in situations where such support is offered, they sometimes decredit family experiences.[8] This reality causes the family to be unprepared to make daily decisions or actions that collaborate with the proper disease control management.

A study conducted in Canada shows that care for people with chronic diseases in Primary Health Care (PHC) has not yet been able to incorporate the social and specific needs of children and adolescents into the practice of services, due to the unpreparedness of professionals in relation to managing chronic and relatively rare childhood conditions.[9] Thus, a systematic study concluded that many hospital readmissions could be avoided if PHC coordinated care with child-centered follow-up care, which would enable the identification of modifiable factors that led to hospitalization.[10]

Thus, due to it being a complex situation, people with chronic diseases need the support of the health team in relation to self-care, in order to ensure better quality of life and to have their needs met. Thus, the importance of professional practise focused on the empowerment of the individual/ family as a mediator of their own treatment plan, through the joint definition of problems, priorities, goals, care plans and continuous monitoring of results is highlighted.

In this context, a specific strategy for supported self-care for people living with chronic diseases in the pediatric age group has the potential benefit of reducing the need for more complex care, contribute to the reduction of costs for the health system, reduce the workload of caregivers and improve the quality of life of this population.[11]

Therefore, it is questioned: what health actions has the PHC team developed to support self-care for children and adolescents with chronic diseases? Thus, this study aims to analyze actions of PHC teams from the perspective of self-care of children and adolescents with chronic diseases.

METHOD

This is an exploratory and descriptive qualitative study conducted with 11 PHC health professionals from a city in Paraíba, from April to August 2016.

Data collection was performed by using the list of 194 Family Health Units (FHUs) linked to the Family Health Strategy (FHS) of the municipality PHC and then subdivided according to the Health District (HD) to which they belonged. In addition, a draw was held to include at least one team from each of the five HDs of the municipality. In each unit drawn, there were approximately five professionals from the minimum team, who were randomly interviewed in a rotation system, i.e., participants from different health categories of each team were included until the interviewer perceived data saturation.

Inclusion criteria were: being a health professional working with children / adolescents with chronic diseases registered in the PHC coverage area and working in the service for a minimum of six months. Those who were: on leave, away or on vacation during the data collection phase were excluded from the study. Thus, two professionals from HD I, III, IV and V and three from HS II participated.

The collection was conducted through semi-structured interviews, recorded on electronic media, with an average duration of 45 minutes each, based on the following guiding questions: What health care actions do you perform for children / adolescents with chronic disease? How do children / adolescents participate in self-care? How do you think you could promote self-care with children / adolescents to help control chronic diseases? All interviews were conducted and transcribed by the lead researcher. The data collection ended when the researcher judged that the collected material met the objectives of the study and that new subjects would not add anything new to the theoretical reflections on the subject.[12]

The interpretation of the empirical material was based on thematic analysis.[13] The fully transcribed interviews were subjected to exhaustive readings for the researcher's impregnation in the field material, by doing a preliminary organization and systematization of the data. Next, the central thematic units were established and an interpretative synthesis was made with inferences from the researcher, based on the theoretical framework inherent to the theme or on findings that could lead to new theoretical dimensions.[13]

The thematic analysis allowed the categorization of self-care actions according to the 5 A´s methodology: assessment - understanding the subjects' beliefs, knowledge and behaviors; guidance - exchange information on disease management and coping strategies and skills training; agreement - elaboration of the joint self-care plan, considering the specificities of the individual; assistance - actions by professionals that improve people's motivation and improve their self-help skills; follow-up - joint development and implementation of a monitoring system.[3]

In order to ensure anonymity, participants were identified by professional category, using the letter E (acronym for interview respondent) and the number according to the sequence of the interview.

RESULTS

The study included three Community Health Agents (HCA), two Dentists, three Nurses and three Doctors, nine women and two men, with an average age of 48 years, ranging from 31 to 65 years.

Regarding the level of education, one professional had completed high school and the others had completed higher education, one HCA was trained in Social Work and the other in Languages and Literature (Portuguese and English); seven of the participants were specialists and one was a resident. Among the total, six had specializations in Family Health, one was in a residency program in the area and only one had no specialization in this area. The length of professional experience of the individuals ranged from 3 to 39 years, with between 3 and a maximum of 15 years in PHC. The time period regarding their current position in PHC ranged from 1 to 14 years.

Promoting actions for supported self-care in children and adolescents with chronic disease

The results will be evidenced through the 5 A´s strategy pillars, where assistance to the individual is initiated with the evaluation of the entire context. Afterwards, guidance is provided on everything that involves the management and coping with the disease, so that agreements can be made on how to keep the disease under control, implemented by the assistance of the professional and the self-care of the individual, and finally the follow-up of results over time.

Evaluation

Evaluation is the first pillar of supported self-care, its function is to verify the skills, abilities, and barriers to self-care, as well as the experience of chronic disease of children and / or adolescents and their families. In this study, the HCA was able to collect information about the barriers that prevented one adolescent from self-care, reproducing her discourse: "*But I* [obese teenager] *ask my mother* [to cook according to the diet]*, mother does not"* [...]*. Because it is complicated for teenagers to go to the kitchen* [...] (HCA, E1).

Assessing the user's emotional state is also a factor that influences their confidence and compliance to perform the necessary actions to maintain their health, as shown in the following statements: [...] [adolescent with lymphoma] *is very optimistic* (HCA, E6). *At first* [the diagnosis of diabetes for the adolescent] *was a shock* [...] (Nurse, E10).

A favorable family environment is also significant in the health-disease process, especially in the pediatric age group: *I think she has a lot of problems in her house, you know?* (ACS, E1). *Yes, we try to see that the child has to live in a conflict-free environment, in a well-adjusted environment so that he does not get sick so easily* (Doctor, E9).

Guidance

Guidance is a pillar that aims to provide information and recommendations on aspects of the disease, the treatment and the evidence on which this knowledge is based. One of the actions included in this pillar is the sharing of knowledge regarding the signs and symptoms of the disease, as well as treatment: *We show the formatio*n [of cavities] [...] *which foods we know cause the most cavities, talk about the issue of food* (Dentist, E4). [...] *and we would just talk about the disease, ask me about the symptoms, if he needed a doctor* [...] (HCA, E6).

However, the education of the professional interferes with their opinion about the importance of health education with these individuals: *Sometimes I thought I was wasting my time talking* [guidance regarding cavities]*, but no, it's the other way around when you stop and explain what that behavior can cause, then he starts to want to do* [treatment] (Dentist, E5).

By showing the user that the adopted behaviors may or may not contribute to their health, the professional values the awareness of behaviors that have an influence as much as the drug treatment: *In his case* [hypertensive adolescent]*, I have already brought him several times to the office to see what he was doing because his blood pressure was not improving* (Doctor, E8).

Agreement

This pillar includes actions aimed at the shared decision of strategies that include setting goals through collaboration between professionals and individuals with chronic disease. This attitude is not prescriptive, it values the autonomy of the individual as the protagonist of their health. However, it should be noted that, in order for this to be effective, one must take into account the age and intellectual maturity of the user.

The individual's trust in the health professional is a factor that encourages these agreements and maintains this connection. Therefore, it is necessary for the professional to preserve what was proposed, so that no negative feelings are generated: *I invent something for her* [diabetic teenager] *to talk about* [with the nutritionist] *there* [...], *she says: "Ah! I won't go, because when you go there, you get away from me"* [...] (HCA, E1).

In addition to the help of health professionals, the encouragement to seek help from a support network of relatives and friends can contribute to the definition of goals: *It would be interesting for him* [adolescent with Lymphoma] *to have contact with these people* [who also have / had cancer] *, who are reinserting themselves in life [...] I said: "But, talk on the internet", that's when he started talking on the internet, I already got a call from someone, I found out that we had mutual friends, it was a connection in the community* [...] (HCA, E6).

Assistance

The assistance pillar portrays the use of effective self-management support strategies that include action planning and problem solving. Thus, the professional can help the person to identify which resources exist in the family and / or community that help self-care: *Also, we were able to refer the child to CRAS* [Reference Center for Social Assistance] *and the child obtained social benefit*. [...] (Doctor, E9).

On the other hand, many actions in this pillar require communication from the multiprofessional team for shared planning: *I see the issue of whether the child is compensated or not, if he/she has diabetes, I will seek information from the nurse* [...] *focus very much in my area, and what I don't know I try to interact with other professionals* (Dentist, E5).

The School Health Program (PSE) is a multiprofessional action advocated by the Ministry of Health, in which activities are developed to detect Systemic Arterial Hypertension (SAH), diabetes, cavities, among others, as well as offering health interventions for disease control, and guidance to classmates and teachers. However, health professionals revealed that they did not have this contact with the school environment of their users: *I haven't had any contact with the PSE* (Doctor, E7).

Follow up

Follow-up is the pillar that brings the outcome of knowledge of the individual's situation in PHC. Regarding its importance for children/adolescents with chronic diseases, only two of those interviewed mentioned doing so: *She* [child with congenital hydrocephalus] *comes to me on a monthly basis, I am a pediatrician* [...] *because it is a chronic disease that requires monitoring* (Doctor, E9).

Other professionals performed general follow-up with children and adolescents in their area, regardless of the chronic condition or age of these users: *It is the same intervention of any decayed tooth. Whether adult, elderly, or child* (Dentist, E4). *Thus, there is no program aimed* [at children / adolescents with chronic diseases], e*specially because there is no significant group to develop a specific program* [...] to *follow up these patients* (Doctor, E8).

One form of follow-up can be through peer groups, where each member can see themselves in each other. However, the inclusion or participation of children or adolescents in the groups developed by the PHC services were not identified in the statements. It should be noted that there are only hypertensive and diabetic adults.

Another effective way to follow up is by performing home visits, which, however, is not always done for this user profile: *Damn, I really wanted to go* [home visit] *when you look at these cases* [children / adolescents with chronic diseases] *that utopian idea of having better follow up* [...] (Doctor, E7). *He* [a diabetic teenager] *is a person who, apart from diabetes, is healthy, is able to come to the unit* (Nurse, E10).

In general, family health teams give HCAs the responsibility of home visits, with other professionals being contacted when they find it necessary: *I think it is important for the HCAs to do home visits because they can look and have an overview of the person, open the child's mouth and already give advice*: *You need to go* [to PHC] *because of this* (Dentist, E5).

The lack of follow-up of children and adolescents with chronic disease in PHC usually occurs because professionals believe that the specialist is responsible for this care. *In general, these case*s [children with chronic diseases] d*o in fact often end up becoming more frequent, more because of the specialist than for us* [...], *and we end up giving a lot of care* [...] (Doctor, E7).

In addition to this, there is also the lack of counter-referral of care provided at the other level of care: *There is no counter-referral* [of the expert]. T*he user comes to the unit* [...], *we know they went because they arrive here already with the laboratory exams, and then we see if they are being properly monitored* (ACS, E1).

Another situation in which there is transfer of responsibility is when users, in addition to monitoring at another level of care, receive care from the complementary health network: *Because she* [child with Down Syndrome] is *treated elsewhere, she attends the Foundation* [State run institution for persons with disabilities], *has health insurance, but nothing by the Unit, only her vaccines are done here*. *There is no link* (ACS, E11).

Therefore, it is possible to evidence that the monitoring of children / adolescents with chronic diseases by PHC remains poor in relation to action strategies for health maintenance and disease control, communication with family and community and availability for closer contact between professional and user.

DISCUSSION

The present study included health professionals with diverse academic backgrounds, who provided explanations of actions in different areas of health care. All of them had considerable professional training and experience in PHC, which allows them to familiarize themselves with children and adolescents with chronic diseases and their families from the area covered by the respective PHC services in which they operate.

As a mediator for the implementation of supported self-care, the 5 A´s methodology can be effective when there is a continuous flow of actions between the pillars. For this to occur, professional commitment is necessary to establish a good bond with children/adolescents and their families, as a way of motivating the practice of self-care,[14] and it is essential that this relationship consists of mutual trust and constant support from the team. In several situations, it was possible to perceive the weaknesses in these bonds with the user.

Therefore, there are times when the relationship has been permeated by the lack of understanding/acceptance of the reasons why changing habits is necessary, which interferes with disease control. Due to this, in addition to extrinsic (professional) motivation, there must be intrinsic (personal) motivation, so that the action can be successful.[14] Such action can be developed by the professional with the user through reflexive listening and motivational interviewing,[3] however, interventions have not been developed in this perspective.

Actions related to supported self-care by assessing the health-disease process of children and adolescents with chronic diseases in PHC, reported in this study, are related to information about their social and family context, barriers and feelings generated by the disease.

In this area, the gaps occur mainly with regard to valuing the individual's opinion in setting goals for disease control. In order to help in the management of the disease, a web-based platform was developed based on the opinion of adolescents about the impact of symptomatology on activities of daily living, at school, with peers, on barriers to self-care, and the stigma and discrimination due to to the invisible nature of chronic pain.[15] This kind of attitude could contribute to user accepting the established actions more easily.

Regarding the feelings that permeate the health-disease process such as anxiety, discouragement and optimism, when the professional identifies the emotional state in their assessment, there are parameters which they can use to recommend leisure activities, consultations with other team professionals, peer stimulation and family support.

The transition processes in the pediatric age group occur from childhood to adolescence as well as from adolescence to adulthood. In this context, the literature has highlighted the need for gradual support in these phases, especially when there is a transition from care in pediatric to adult services. This transition should be initiated months before, so that it does not just become a transfer from one type of service to another,[16] influencing the relationship with professionals and compliance to care.

Regarding the advice provided by professionals, there were no actions consistent with the provision of educational materials on self-management of the disease according to the individual's maturity, nor on sharing clinical evidence that may encourage active participation in treatment or modification of harmful habits. In general, for children and preadolescents, responsibility for self-care is centered on the primary caregiver figure.[17]

One study[18] states that, as a result of the child's chronic condition, the family accumulates indispensable knowledge regarding daily care, which, over time, will be learned and performed by the child himself. However, the construction of this knowledge must be supported by health professionals, through dialogue, and the exchange of knowledge and information.

Given the centrality of self-care of the main caregiver, professionals have perpetuated an indirect attention by returning actions and information to the family, instead of valuing the child / adolescent in a singular way. It is understood that, in addition to working with the family in the empowerment for care and even in the perspective of this institution accepting the transition of care for the child, the professionals should include the child/adolescent in the decisions, asking them questions about their state of health using an age-appropriate approach.

The clarification, preparation and support to children about the disease and painful procedures can be performed using the Therapeutic Toy, as used in a study[19] in which children who experienced this technique before being vaccinated had greater acceptance of the procedure. Another resource that could facilitate pediatric consultations with these children could be performing them in groups, which would allow the clarification of more frequent doubts and the exchange of information between caregivers, mediated by the PHC health team.

In the agreement pillar, the gaps resulted from the lack of actions in the perspective of valuing the interest of the user and their confidence in the implementation of strategies beneficial to their experience regarding the illness. In this pillar, in addition to listing the objectives for change, one must also take into account the barriers that hinder self-care. When children and adolescents are not included, they may feel lonely and unsupported, making it difficult to control the disease,[20] as they assume a passive position in the care of their health.

In the assistance pillar, there was a lack of actions aimed at care that allows the individual to be the protagonist in self-care and groups on disease management. In addition, the use of technologies that provide user reach in any location has not been explained.

It is possible that the scarcity of actions aimed at the active participation of people living with chronic disease in defining the goals they want to achieve, as and when this is possible, may also be due to health professional training, which is still rooted in protocols and the hierarchical relationship in which users listen and try to reproduce the guidelines, regardless of their needs or ability to comply with them.[21]

The involvement of the multiprofessional team gives a feeling of security and allows the development of skills in procedures performed at home.[22] However, a lack of institutional care with individuals was identified, highlighted by the isolated nature of the professionals' work, each focused on their area, without the necessary integration.

Regarding follow-up, the gaps are exemplified in the transfer of responsibility to the specialist, aggravated by the lack of counter-referral to PHC. One study confirms these findings by stating that the lack of links between services is a disadvantage to this pillar and causes inefficient health care.[23]

Corroborating situations of transferring responsibility from PHC to specialized services, a study with 71 relatives of children and adolescents with HIV identified the specialized service as the main source of care, rather than the nearest health care service, which, in most cases, was PHC.[24] This situation contrasts with the provisions of Ordinance 483/2014, which names Primary Care (PH), as a PHC service, as the coordinator of the Health Care Network, and responsible for providing comprehensive and continuous care to the population in their coverage area, focused on the prevention, diagnosis, screening and treatment of chronic diseases, as well as the possible complications arising from them. When their treatment options are exhausted, they can be referred to Specialized Care, without, however, exempting them from the responsibility for coordinating care.[25] Given the above, clinical treatment can be monitored by a specialist, but it is the PHC team who should be co-responsible for accompanying the family in managing the health care of these individuals.

Regarding chronic diseases, it is important to understand that each case should be treated individually in the long term. Thus, monitoring users can be optimized with the implementation of strategies such as home visits, which are a way to perform active searches, as they allow the professional to dialogue and observe the reasons for the users absence or analyze the health situation of families.[26]

Although it is an important work tool in PHC, the literature highlights that the home visit by all team members is weakened.[23] In this study, it was evidenced that the home visit is the responsibility of the HCA, who acts on obtained knowledge and what is identified. These professionals have a very important role in the work process of the teams, since they are the link between the community and the health institution. When there is an effective bond in this relationship, the HCA can motivate the individual to go the PHC service. However, this agent does not have professional training to diagnose specific demands related to other professional categories, which may compromise family care.

Follow-up can also be made possible by meeting with peers - people living with the same disease - and by supporting the community to help support their self-management.[27] However, there was no specific groups for people in this age group, and the strategies used for adults are not attractive to children/adolescents. In the literature, this obstacle has been circumvented by the formation of online peer groups, mediated by health professionals, to help adolescents with chronic diseases in the transition phase from pediatric to adult care.[28] Thus, free online messaging applications could be used as alternatives for case follow-up.

Another form of support for the self-management of children and adolescents with chronic diseases is the partnership of PHC professionals with the school community, in order for them to perform PSE activities. One study has shown the benefit of such actions in controlling diabetes by providing information and implementing interventions in the school.[29]

Given the analysis, this study contributes to the area of Nursing and health by highlighting the actions that have been performed in the FHS with children/adolescents with chronic diseases and their families, even with the limitation of having been performed in only one municipality and not allowing generalization of the findings to the entire population of Brazilian PHC professionals. Dissemination of this information can help to change professional-user relationships from the perspective of making the individual a protagonist of their self-care, without removing the responsibility of disease control from the health team.

CONCLUSION

By analyzing PHC team actions, from the perspective of supported self-care of children and adolescents with chronic diseases and their families, it was found that none of the participants reported actions in all pillars of the 5 A´s methodology.

The interventions which were reported were generally on the assessment of barriers to self-care and the emotional state of the individual; providing information on the signs and symptoms of disease and treatment; stimulating the search for community resources that can assist in this process; care and assistance through health actions inherent to the professional training of each one; and follow-up, using active search and home visits. These actions are still incipient and not unanimous among the participants. However, they correspond to the beginning of a co-responsibility for the health situation of these individuals.

Finally, it is noteworthy that the health actions evidenced in this study do not yet value the active and co-responsible role of the individual in the disease control. There are several gaps to be overcome in each of the pillars. Thus, intervention studies that aim to train and sensitize health professionals regarding the development of actions that contribute to the improvement of the routine of children and adolescents with chronic diseases, and supporting the self-care management of these individuals are recommended.

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NOTES

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CONTRIBUTION OF AUTHORITY

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CONFLICT OF INTEREST

No any conflict of interest.

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