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RESEARCH

CHALLENGES FOR THE CARE OF FAMILIES OF CHILDREN WITH DISABILITIES IN PRIMARY HEALTH CARE

DESAFIOS PARA O CUIDADO ÀS FAMÍLIAS DE CRIANÇAS COM DEFICIÊNCIA NA ATENÇÃO PRIMÁRIA À SAÚDE

DESAFÍOS PARA EL CUIDADO DE FAMILIAS DE NIÑOS CON DISCAPACIDAD EN LA ATENCIÓN PRIMARIA DE SALUD

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ABSTRACT

Objective: to know the care actions carried out by Primary Care professionals to the families of children with disabilities. **Method:** qualitative study, based on the philosophical framework of Patient and Family Centered-Care, carried out in one of the six health districts of a capital of the Brazilian Midwest. Informants were 41 health professionals who worked in the Family Health Strategy teams, linked to the Basic Health Units, which had children with disabilities living in their area of coverage. Data were collected from June to August 2018, through semi-structured, audio-recorded interviews, and submitted to Content Analysis. **Results:** health care is centered on the clinical aspects of the child's disability, does not include the family in care, nor does it recognize their demands, beliefs, autonomy or needs related to care. Assistance is provided based on spontaneous demand, is restricted to home visits, dispensing with materials and medicines and referrals to specialties related to disability. Their actions are not systematized, nor are children followed longitudinally or their families included/ considered in assistance/care. **Final considerations:** health professionals working in this scenario need specific training so that the assistance provided to families of children with disabilities is focused on the integrality of care and the needs of the child and his family, recognizing their potential, and the importance of their autonomy and participation in care.

Keywords: Disabled Persons; Child; Family Health Strategy; Primary Health Care; Health Care.

RESUMO

Objetivo: *conhecer as ações de cuidado realizadas pelos profissionais da Atenção Primária às famílias de crianças com deficiência.* ***Método:*** *estudo qualitativo, fundamentado no referencial filosófico do Cuidado Centrado no Paciente e na Família, realizado em um dos seis distritos de saúde de uma capital do Centro-Oeste brasileiro. Foram informantes 41 profissionais de saúde que atuavam nas equipes da Estratégia Saúde da Família, vinculadas às Unidades Básicas, que possuíam crianças com deficiência residentes em sua área de abrangência. Os dados foram coletados no período de junho a agosto de 2018, mediante entrevistas semiestruturadas, áudio-gravadas, e submetidas à Análise de Conteúdo.* ***Resultados:*** *a atenção à saúde é centrada nos aspectos clínicos da deficiência da criança, não inclui a família nos cuidados e nem reconhece suas demandas, crenças, autonomia ou necessidades relacionadas aos cuidados. A assistência é realizada a partir da demanda espontânea, se restringe às visitas domiciliares, dispensa de materiais e medicamentos e encaminhamentos para especialidades relacionadas à deficiência. Suas ações não são sistematizadas, nem as crianças acompanhadas longitudinalmente ou suas famílias incluídas/consideradas na assistência/cuidados.* ***Considerações finais:*** *os profissionais de saúde atuantes*

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neste cenário necessitam de capacitação específica para que a assistência prestada às famílias de crianças com deficiência seja focada na integralidade do cuidado e nas necessidades da criança e de sua família, reconhecendo suas potencialidades, e a importância de sua autonomia e participação no cuidado.

Palavras-chave: *Pessoas com Deficiência; Crianças; Estratégia Saúde da Família; Atenção Primária à Saúde; Atenção à Saúde.*

RESUMEN

Objetivo: *conocer las acciones que realizan los profesionales de Atención Primariapara cuidar a las familias de niños con discapacidad.* ***Método:*** *estudio cualitativo en base al marco filosófico de atención centrada en el paciente y en la familia, realizado en uno de los seis distritos de salud de una capital de la región centrooeste de Brasil. Participaron 41 profesionales sanitarios que trabajaban en los equipos de la estrategia Salud de la Familia vinculados a las unidades básicas y que atendían a niños con discapacidad residentes en su área de alcance. Los datos se recogieron entre junio y agosto de 2018, a través de entrevistas semiestructuradas, grabadas en audio y sometidas a análisis de contenido.* ***Resultados:*** *la atención de la salud se centra en los aspectos clínicos de la discapacidad del niño, no incluye a la familia ni reconoce sus demandas, creencias, autonomía o necesidades relacionadas con el cuidado. La atención se basa en la demanda espontánea, se limita a las visitas domiciliarias, entrega de materiales y medicamentos y derivaciones a especialidades relacionadas con la discapacidad. No se sistematizan sus acciones, ni se hace seguimiento longitudinal a los niños, ni se incluye o considera a sus familias en la atención o cuidado.* ***Conclusión:*** *losprofesionales de la salud que trabajan en este escenario deben estar capacitados para que la atención brindada a las familias de niños con discapacidad se enfoque en la integralidad del cuidado y en las necesidades del niño y su familia, que se reconozcan sus potencialidades y la importancia de su autonomía y participación en dichos cuidados.*

Palablas clave: *Personas com Discapacidad; Niño; Estrategia de la Salud Familiar; Atención Primaria de Salud; Atención a la Salud.*

INTRODUCTION

In Brazil, it is estimated that 10% of children are born or acquire some type of disability throughout their lives (physical, hearing, visual, intellectual or multiple) that can trigger limitation of functions, activities or social role, dependence on compensatory mechanisms, need of care actions that meet the specifics, in addition to the continuous use, above the usual, of health services.[1,2]

Families of children with disabilities experience changes in structural organization, triggering changes in their family dynamics, redefinition of roles and physical and emotional overload. The monitoring of these families by health professionals is essential, as they need preparation to adequately care for the child and support to carry out their self-care[3], and help to recognize their own needs, as it is common to choose child care as the most important, if not the only, priority.[4]

Children with disabilities are sometimessubject to prolonged hospitalizations, more frequent readmissions, and complications in the prognosis. For this reason, it is essential to guarantee them, via the Unified Health System (*Sistema Único de Saúde* - SUS), the right to health at all levels of complexity, which constitutes a challenge for health services.[5]

In this scenario, primary health care (PHC) and, more specifically, the teams of the Family Health Strategy (FHS) should be the main doors of entry for these families into the health system. This is because the actions and strategies developed in PHC can facilitate access and ensure that the therapeutic itinerary of these children occurs according to and from their specific needs, in addition to those of their families.[2,6]

The timely performance of these teams should also favor the continuity of care, a central component for integrality and longitudinality[7], which are basic precepts of PHC.[8] However, the growth in the number of children with chronic health conditions and with specific care demands has implied daily challenges not only for families, but also for health professionals, especially those working in PHC, who need to be prepared to welcome this population and ensure quality and equitable assistance.[9]

Some studies have revealed that the attention given by FHS teams to children with disabilities is fragile, disjointed and discontinuous, which has led some authors to infer that this may be related to the professionals' lack of preparation to meet the needs of this population.[10,11]

A study carried out in *Recife* (*PE*, state of *Pernambuco*, Brazil) with mothers of children with microcephaly showed that care for these children needed to extend to the family, which has a determining role in care and rehabilitation and needs to be helped and supported by health professionals, especially those from PHC. This is because, because they are inserted in the community, these professionals have more access and bond with the family, which positively influences the monitoring and provision of guidance to families, considering the different home realities.[12]

It is worth mentioning that the bond between the family and health professionals is fundamental for the promotion of quality care for the child and also for promoting the well-being of the whole family. However, for this to occur, universal, integral, continuous and resolutive assistance is required, based, for example, on the principles of Patient and Family-Centered Care (PFCC), as the involvement of the family in the planning of care is essential for there to be more resoluteness in child development.[13]

Considering this scenario and the need for differentiated assistance, the use of the PFCC precepts in conducting assistance appears as a promising possibility. It is a philosophy intended to unite the care provided by the multiprofessional team, giving voice to the patient and his/her family, respecting their values, and considering their importance in the recovery of the patient's health.[14,15]

It should be noted that, when adopting the PFCC as a reference for the performance of professionals, it becomes necessary to consider it in planning, in the execution and in the evaluation of the health care offered.

It is important to note that this approach corroborates the health policies that guide the practice of professionals in the context of PHC, especially with regard to the valorization of care aimed at the individual and his/her family. Thus, when using the PFCC framework in the organization of health services and in professional practice, the level of health care and the scope of assistance are expanded.[16]

The precepts of the PFCCs are likely to be adopted within the PHC scope, as they are in line with their basic precepts regarding the need to consider the family as the focus/object of attention, which requires interaction between the health team and this social system and extensive knowledge of your health problems. It also requires the development of skills that allow the team to approach the family and build a working relationship that promotes more appropriate care for children and their families.[17,18]

Despite these advantages, as far as is known, this framework has not been used in the context of PHC. In this sense, the question is: how is the assistance offered to families of children with disabilities by professionals working in PHC? What care actions are performed? What makes this assistance easier and more difficult? To answer these questions, the objective of the study was defined: to know the care actions carried out by primary health care professionals for the families of children with disabilities.

METHOD

This is a descriptive study, with a qualitative approach, supported by the philosophical framework of PFCC[13], developed in line with the criteria established by the Consolidated Criteria for Reporting Qualitative Research (COREQ).[19]

The study was carried out in one of the six health districts in a capital of the Brazilian Midwest. The district maintains 12 basic family health units (BFHU) that, in the scope of Primary Care, assist a population of around 185 thousand inhabitants, living in 14 neighborhoods. This health district was selected for convenience, as it corresponds to the area of activity of the university's health courses to which the research is related.

Health professionals participated in the study (community health agents [*agents comunitários de saúde* - ACS], nurses, Nursing technicians and doctors) working in the 12 BFHU, as they all met the criterion of having a register of children (zero to 12 years) with disabilities in their scope area. Professionals who were on vacation (seven) or on sick leave (six) during the period for data collection in each BFHU did not participate. It should be noted that all invited professionals agreed to participate.

The professionals' initial approach to request participation in the study was carried out in person and given the agreement, the most convenient day and time for the interview was scheduled, so as not to jeopardize the service routine.

Data were collected from June to August 2018 through semi-structured interviews conducted in a reserved room at the BFHU, by the main researcher. They were audio-recorded after authorization, had an average duration of 15 minutes and were guided by a script consisting of two parts: a) questions related to the characterization of the participants; b) guiding question: "how is the assistance to families of children with disabilities carried out by you and your team?" Some support questions were used when necessary: do you feel prepared to assist these families? Talk a little more about it. In your opinion, what favors and what hinders this assistance? How do you think it should be?

For the analysis, the interviews were transcribed in full, preferably on the same day they were conducted, and subsequently, all material was manually submitted to content analysis, thematic modality, using the three steps proposed: pre-analysis, exploration of the material and treatment of the results obtained and interpretation.[20] In the pre-analysis, data organization and exhaustive reading of the interviews were carried out, with identification of the recording units. In the exploration of the material, the data were coded, and the provisional categories were identified. Finally, in the data treatment and interpretation stage, the codes were grouped by similarity, with confirmation of the provisional categories, followed by inference about their relationships and interpretation in the light of the theoretical framework of the PFCC.

The project was approved by the Human Research Ethics Committee, of the *Universidade Federal do Mato Grosso do Sul* (Opinion Report Nr. 3.354.928). All participants signed the Free and Informed Consent Term (ICF) in two copies, a copy forthe participant and another for the researcher. In order to preserve anonymity, the excerpts of the statements were identified by the ENF codes for nurses; MED - doctor; TE - Nursing technician; ACS - community health agent; and a number indicating the order of the interviews.

RESULTS

Of the 41 health professionals participating in the study, there are: 14 *ACS*, 13 nurses, eight Nursing technicians, six doctors, who were aged between 25 and 65 years (mean of 37 years), and have been working in theBFHU from one to 12 years. It is noteworthy that 16 professionals reported having contact with children or adults with disabilities outside the professional scope and 28 stated that they did not fully know the public policies aimed at this population.

From the qualitative analysis of the data, two categories emerged: "weaknesses in the care actions for children with disabilities and their families"; and "challenges for care-centered on children and families", which are discussed below.

WEAKNESSES IN THE CARE ACTIONS FOR CHILDREN WITH DISABILITIES AND THEIR FAMILIES

The family of the child with a disability is a hidden instance in the care of FHS health professionals, as the relationship with them is established specifically in response to the fact or incident related to the child that motivated the search for the service.

These families are identified and known by the ACSas residents in their assigned area, but the actions and care provided by health professionals follow the same perspective as is generally provided to other children, with no attention or action being implemented or differentiated, respectively.

> *The ACS identifies this child, so I go after the child, conduct a home visit, and see if there is a need for other professionals, then they will also go* (ENF-7).

> *In this case, it is a child who comes to a normal childcare consultation, like any child* (MED-10).

> *The follow-up is normal, automatic, just like the others, it does not change anything, it only shows on the spreadsheet that you have a disability and what you have, did you understand?* (ENF-4).

> *The follow-up is normal, the only thing is that we have to look precisely at these public policies, so that it would have priority, there would not be constraint, right?* (TE-5).

> *We follow-up as a normal child in the area, you know? to know how the development is going* (ACS-5).

The professionals' attention is directed exclusively to children with disabilities and is subject to the health demand presented by the family.

> *We conduct a home visit, you know? the monitoring is monthly, every month we visit to see how the situation is, we weigh them, measure them, see the vaccination card and meet the demands of those who ask me, of what I see they are in need* (ENF-4).

> *Monitoring the family as a whole, not only in the disability* (ACS-5).

> *If there is a need, we follow-up everyone, but it is more aimed atchildren* (ENF-6)

> *There is nothing specific for the family, it is more like a clinical approach, it is in general, like any patient* (ENF-9).

> *We visit, as a doctor I play my role, but there is nothing specific, no educational activities, nothing is planned* (MED-9).

The home visit was considered by professionals as an action carried out with the family, as they believe that the family is included because the visit is carried out at home. The appreciation of the child's specificities, the approach taken with this audience, the orientations and referrals are actions highlighted by the professionals. In relation to the family, welcoming actions and orientations offered to the main caregiver are considered actions, with whom professionals often establish communication.

> *What we can do in relation to the family is the welcoming* (ENF-7).

> *It depends on the need the family asks for, then we do it* (TE-4).

> *We pay a monthly home visit, but she is free to come here, if she wants to, if she needs something* (ENF-12).

> *I advise on the programs that are available in the unit, such as vaccination* (ACS-7).

When asked about the resoluteness of monitoring the families at the BFHU, the professionals showed they believe on that, as far as possible, they try to do what is available to them and the service - vaccines, consultations and medicine dispensing. They also stressed the need that families of children with disabilities have in relation to being able to take advantage of services of greater complexity and specialized professionals. And they consider that, if the structure and the service allowed, it would be possible to offer more to the child and the family.

> *As far as possible yes, here* [BFHU] *there is a lot that we are unable to do* (TE-10).

> *Not all* [needs], *because we are unable to provide care in a basic unit, they need secondary care* (ENF-10).

> *Basic needs, yes, such as medicines, consultations, vaccines, then what no longer depends on the unit, no* (ACS-6).

> *So, this issue is difficult, because if there were more things here, they could come here which is closer and not go there at* APAE (*Associação de Pais e Amigos dos Excepcionais*) (ENF-6).

> *I think so, just some things that due to the lack of material or specialist we are unable to do* (MED-6).

Participants reported the need for more integration between the different levels of care, as they consider that case management is not enough when performed only in the PHC.

> *We cannot care for a special child in a basic health unit, you know? they need secondary care, but whatever is possible to do we do*(ENF-10).

> *In these specific rehabilitation cases, we cannot manage here in the primary care, we should know or be able to do it, but we cannot, we have theFamily Health Support Center* (NASF, *Núcleo de Apoio à Saúde da Família)team that cannot meet everyone needs, the demand is very high* (MED-10) .

In relation to public policies aimed at children with disabilities and their families, the professionals demonstrated restricted knowledge, sometimes shortened in preferential care. It is observed that, although the professionals recognize the existence of guaranteed rights to this population, they do not really know them.

> *I know it exists; I do not know it in depth* (ENF-1).

> *I will not say yes, but we know a little* (ACS-2).

> *It is worse for I do not know it* (TE-3).

> *I know, not deeply, but I know, I know that this type of patient has several* NE *rights* (MED-3).

CHALLENGES FOR CARE-CENTERED ON CHILDREN AND FAMILIES

The professionals report that there are limitations in the scope of the service structure that hinder the inclusion of the family in the care process and planning, for example, the insufficient number of material and human resources. For them, excessive bureaucracy, high demand for activity and lack of preparation discourages them from offering family-centered care. Not having specialists in the unit is also considered a difficulty for the care of children and their families.

> *It is bad because of this material issue that we feel a little helpless, because in most months of the year there is no material* (ENF-11).

> *Sometimes we even want to do more, but there is a lot of bureaucracy, you know? everything has to be authorized, sometimes there is a shortage of material, sometimes things are missing* (ACS-12).

> *Due to the lack of material or even the lack of a specialist that we are unable to support children and families, then in these cases we have to refer them* (MED-6).

The professionals consider that there is not the necessary infrastructure so that they can adequately assist children and families, as some BFHU are installed in adaptedplaces, which makes this public's accessibility to services unfeasible. In these specific cases, not having accessibility implies not guaranteeing dignity and respect for these children and their families and the minimum condition for their care.

> *Accessibility, they have a lot of difficulty, here it is very bad, it lacks a lot, there is a lack of structure [...] there is a lack of structure for the* NE (ENF-3).

> *This, when thinking on an infrastructure problem, because the problem still exists* (MED-4).

> *There is a lack of a look towards accessibility in health units, do you understand? Here is a house that was set up to be* [UBSF] (TE-5).

In the perception of these professionals, these children and their families do not need the services offered at BFHU, as they have already received the indispensable care to their demands in special health and rehabilitation institutions. Thus, they focus their attention on providing the support they deem necessary to families when they seek care at the unit.

> *She sometimes comes here, looking for, let's suppose, accessories, the things she needs, here it is, but her monitoring is no longer here, do you understand? It is with the specialist doctor, just like I told you, in another location* (ACS-9).

> *In this case, we would be a support for her, it would not be the main support, because her main support would be at APAE, she is monitored there* (ENF-6).

> *She has been already monitored, she has already gone to APAE, so in this case she does not need any other follow-up, she does not need anything specific to ask for* SUS (ACS-5).

Professionals feel the need for integration between child and family care services for their continuity and monitoring in the unit. The lack of description of a guiding flow of care for these children's families in institutional policies implies actions based on a biomedical model, characterized by technicality. Such a professional approach does not allow the inclusion of the family, the information shared between the team and the services and the making of joint decisions.

> *We always refer to the specialized service, but we have no counter-referral, so the child almost never comes back to us* (MED-10).

> *Look, they are monitored at* APAE, *so there is practically all the care they need, thus they hardly use it here* [UBSF] (ACS-9).

The professionals revealed that they do not feel qualified/prepared to care for the families of children with disabilities, as there are no continuing education actions offered by the service that enable them to plan and implement family-centered care. They recognize the need to be instrumentalized to carry out this type of approach for the family's engagement in care planning.

> *No, I do not feel prepared, in fact, I am learning on a daily basis, you know? Because I have no education* (ACS-1).

> *I do not feel sorry* [laughs], *not very prepared, we have several training courses at the city hall, but until today, a year that I am there, there has never been anything focused on the area of physical disability, family, nothing* (ENF-3).

> *We are never prepared; we always need to improve* (MED-10).

DISCUSSION

The actions of professionals aimed at the families of children with disabilities in the BFHU show the weakness in the approach of the family and the challenges to maintain assistance that includes the family in all spheres of care.

The PFCC philosophy is categorical in stating that the family should be considered as an essential member of the health team, especially the families of children with disabilities, as they face difficulties in home care and need collaborative actions with the team that guarantee dignity, respect and shared information. In line with this philosophy, it is emphasized that, in Brazil, the main reference used to guide actions in relation to the inclusion of the family in care contexts is the National Humanization Policy (*Política Nacional de Humanização* -PNH).[21]

SUS has as its principle the guarantee of universal and equal access to health actions and services for all people, and one of the points of attention of this system is PHC, which develops actions for promotion, prevention, rehabilitation and treatment in different cycles of health. life. Among its fundamental principles, longitudinality and integrality of the care provided by the FHS teams stand out.[22]

The care actions performed and recognized by the professionals occur discontinuously, both for children and their families. This goes against the precepts of comprehensive care, which propose that the person be considered part of a whole, inserted in a social and family environment. This way of caring also violates the assumptions of the PFCC, which emphasize the importance of family participation in care planning and decision making. In addition, the care network where the child is accompanied in his chronic health condition does not articulate with the services available in primary care.

It was observed that the professionals direct care actions when the family seeks the service to meet the child's punctual demand, which is not consistent with the basic attributes of the PHC, which lead to comprehensive, longitudinal, and continuous care. This condition was also found in studies that found that the monitoring of children and their families by the FHS focuses on disability, its signs and symptoms and on polls, administration of medications, dressings and guidance on aspiration and administration of diets.[17,23]

Likewise, a review study highlighted the appraisal that is given in Nursing care to clinical aspects related to the child's chronic condition and concluded that the care for these children and their families should consider the whole, and not be restricted to biomedical care.[24]

Regarding this, so that health actions are not limited to the identification of the child's clinical conditions, it is necessary to offer comprehensive care that contemplates the biopsychosocial aspects, not only of the children, but also of their family, enabling the knowledge of experiences significant for both and the recognition of potential.[25]

The fragmentation of care directly impacts access, the use of services and the integrality of care provided at different levels of care. For continuity of care, health actions need to take place in an integrated manner among all levels of assistance[26], and the communication process between them must play a central role.

The results found in this study show the lack of communication between the professional and the family. A study conducted in the United States with relatives of children in complex health conditions showed that the deficiency in communication and coordination of the health system often results in a lack of accessible and consolidated information regarding the condition of the child and his family.[10]

In addition, the information shared between the professional and the family is essential for them to feel empowered to face the complications that the child may present and for the proper decision-making, one of the assumptions of the PFCC.

In the state of Rio Grande do Norte, a study with 13 professionals led the authors to conclude that PHC has weaknesses in its role as a family care provider, as it does not bring together material, technological, operational and organizational conditions that allow it to be the main reference of the family for care.[27] Despite the insufficiency of material and structural resources to meet the needs of these children and their families, it is emphasized that the health team has the role of facilitating the access of children with disabilities and their families to adequate care, quality and on time.[28]

It should be noted that families sometimes experience exhaustive demands with children, because, depending on their physical and intellectual condition, they require continuous care and frequent travel to rehabilitation centers. Even with public policies, families still follow, with their own resources and conditions, the itinerary for treatment, rehabilitation, and health promotion for their children. Thus, they need to be seen and welcomed by health professionals in the care of children and a support network that helps them to manage and reconcile their role and the care given to children with disabilities.[29]

For professionals to recognize the family as a care unit and transform individualistic care, centered on the child's clinical condition, into democratic, comprehensive care based on mutual agreement between the team and family, it is necessary for health professionals and managers to become aware about the importance of family participation in the entire care process and provide resources that support professional practice, having the PFCC as a philosophy.[26,28]

It is essential that PHC professionals develop skills to care for the families of children with disabilities, recognize and accept their health demands; bond with them; promote articulation and integration between different levels of care and respect beliefs and habits, which is in line with the attributes of PHC and the philosophy of PFCC.[17,18]

To be prepared to provide comprehensive assistance to this population, professionals need to constantly seek education, updating and training. It is noteworthy that the responsibility for improving knowledge in relation to this theme is not only of institutional management, but mainly of the professionals themselves, because they are activities complementary to their training.[25]

As a limitation of this study, the fact that it was carried out with health professionals belonging to the FHS of a health region in the municipality stands out, which does not allow assumptions about how the care actions carried out by professionals to families of children with disabilities in municipal scope.

There is a need for studies with greater scope and with family members, so that they can express how they perceive themselves to be cared for by health professionals in PHC.

FINAL CONSIDERATIONS

Health professionals practice fragmented care, centered on the specific needs of children with disabilities and recognize that the scarcity of material and human resources and insufficient professional training and qualification make it difficult for the family to be included in the planning and implementation of care. In addition, the absence of a reference and counter-reference system for the continuity and monitoring of the work carried out with the child and the family.

The data reveal that the actions are mainly directed at children, with the family being little considered as the subject of the professionals' attention. So, it becomes important to extend the actions to the health demands and needs of both children and the family. It is also necessary to invest in professional training and on-the-job training and to develop studies that may indicate effective strategies for assisting the family of children with disabilities.

It ends by saying that the articulation between the health team and the family enables care actions from the perspective of integrality, so that professionals consider the family to be an agent involved in care, valuing their autonomy, their feelings and their needs as central elements for the consolidation of primary health care.

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