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Original Article

Primary Health Care to meet families of children with special needs

Atenção Primária à Saúde para atendimento às famílias de crianças com necessidades especiais

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ABSTRACT

Objective: to understand the organization of the Primary Health Care service to meet families of children with special needs. **Methods:** qualitative research, developed with 33 professionals, through semi-structured interviews. We used thematic categorical analysis, with the aid of the WebQDA® software. **Results:** we raised two categories: Strengths and weaknesses in the organization of the care of children with special needs, which showed ambiguity in the assistance in relation to the understanding of the rights and participation of families in the follow-up; and Infrastructure of services for meeting children with special needs, where limitations were expressed in the organization of services and in Health Care Networks. **Conclusion:** we perceived ambiguity and unpreparedness of services in relation to the care of these children, in the qualification of the team, as well as the lack of specific protocols to standardize this assistance.

Descriptors: Disabled Children; Primary Health Care; Child Health Services; Family.

RESUMO

Objetivo: compreender a organização do serviço de Atenção Primária à Saúde para atendimento às famílias de crianças com necessidades especiais. **Métodos:** pesquisa qualitativa, desenvolvida com 33 profissionais, mediante entrevista semiestruturada. Utilizou-se da análise categorial temática, com auxílio do *software* WebQDA®. **Resultados:** emergiram duas categorias: Potencialidades e fragilidades na organização do atendimento às crianças com necessidades especiais, a qual evidenciou ambiguidade na assistência em relação à compreensão dos direitos e participação das famílias no acompanhamento; e Infraestrutura dos serviços para atendimento às crianças com necessidades especiais, na qual foram expressas limitações na organização dos serviços e nas Redes de Atenção à Saúde. **Conclusão:** notou-se ambiguidade e despreparo dos serviços em relação ao atendimento dessas crianças, na qualificação da equipe, bem como na exiguidade de protocolos específicos para normatizar tal atendimento.

Descritores: Crianças com Deficiência; Atenção Primária à Saúde; Serviços de Saúde da Criança; Família.

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Introduction

Established as a model of health protection, the Brazilian Federal Constitution recognizes that health is the right of all and a duty of the State, with Primary Health Care services being the main gateway to the Unified Health System, based on universal coverage and provision of integral services, organized from the Health Care Networks(1), which favor the articulations among services, thereby enhancing comprehensive care(2).

The principles of integrality and equity of the Unified Health System also appear as leading guidelines of the Care Network for People with Disabilities, with the inclusion of actions in Primary Health Care, developed by professionals who know the dynamics and the everyday life of the community(3).

People with disabilities are those who have long-term incapacities, whether physical, mental, intellectual or sensory. They are individuals who come into contact with various obstacles that may cause the interruption of their integral and full participation in society, on equal terms with others(4-5). Among these people, there are children with special needs, those with disabilities and chronic problems of physical and/or behavioral development, which entail an impact on quality of life(6). According to the National Child Health Survey, in 2016, 19.4% of children and young people had special health needs(7).

Children with special needs have general health needs like the others; however, with greater intensity and frequency, which can also be more diverse and extensive. Therefore, they need access to quality services that meet their needs, as well as their families, and that support them in the transition to new and different services. The home care service has been associated with the decreased hospitalization rates of these children due to complex chronic conditions. In order to obtain positive results, children with special needs need strong and positive support networks, including families, health care providers, among other services(8).

In order to ensure the ability of families to care for a child with special needs, it is important that support is available to meet the child's health needs, since the family is the main source of strength and support. In order to assist families, professionals need knowledge to subsidize them in the management of these children; for this purpose, it is necessary to observe the interaction between the child's health and the family structure, as these families have a high level of stress, where the support of Primary Health Care professionals have an impact on the ability to care for these families(8).

It is important that health, education and community institutions develop an alliance between the family and the services, with a common goal in the best interests of children with special needs; for this purpose, they need to take into account the needs, strengths and weaknesses of these children and families. These activities may produce extensive and profound impacts on the physical, social, financial and emotional aspects of families(8), where health services are challenged to support and follow-up families in the care of these children(9).

The experience in caring for children with special needs in the multidisciplinary residency in Family Health Strategy has instigated our interest in the addressed topic. The research is justified by considering it indispensable to check the way in which the organization of the Family Health Strategy can provide a usual source of care, which is important to optimize the health care, the functioning and the quality of life of these people, as well as the future challenges of lives, since the access to Primary Health Care can ensure good health outcomes for these children(8). In order to enable the community to fully enjoy the Unified Health System, the empowerment of the population and the quality of the population relationship with services are essential(7), in addition to longitudinal follow-up and with responsibility for strengthening the coordination of care(3).

In light of the foregoing, we have questioned: how is the health service organized to care for children with special needs from the viewpoint of Primary Health Care professionals? Accordingly, the objective was to understand the organization of the Primary Health Care service for the care of families of children with special needs.

Methods

Qualitative research, whose data collection took place during the first semester of 2019, in a town in the metropolitan region of Curitiba, PR, Brazil. The organization of health services in the municipality is subdivided into three health districts, with a total of 25 Health Units, of which 18 are organized by the Family Health Strategy and 7 by primary care.

In order to select the participants, two Health Units with a Family Health Strategy were drawn by Health District, with a view to obtaining representativeness of the local context. One representative from each professional category of the Family Health Strategy team by Health Unit was elected: Community Health Worker, Oral Health Assistant, Dental Surgeon, Nurse, Physician and Nursing Technician. We chose to interview all professionals who made up the health team, as they are perceived as protagonists in the health care of children with special needs.

Data were collected through semi-structured interviews with 33 health professionals from six Health Units in the local Family Health Strategy, lasting approximately ten minutes. The interview script covered: data from the participants, organization of care in the Health Units and rights of children with special needs. In order to cover the studied phenomena, we employed the guiding question: what are the facilities and difficulties in caring for children with special needs? The complementary questions were: how are children with special needs treated in this service? How does the referral and counter-referral of care of these children happen?

The interviews were recorded in audio, using a digital recorder, transcribed in a document in Word® format and analyzed in their completeness, through the technique of thematic categorical analysis(10). The analytical technique used allows us to divide the speeches collected into thematic categories, in order to, effectively, identify the answers to the study object, thereby allowing the researcher to infer and interpret the collected data(10).

Data analysis enabled the results to be grouped into two thematic categories, which were exemplified with significant passages and organized in the WebQDA® software, version 2017. The interviewees were represented by letters, according to the professional category (taking into account the Portuguese language): Oral Health Assistant (AB), Community Health Worker (AC), Dental Surgeon (D), Nurse (E), Physician (M) and Nursing Technician (T), and numeral, in sequential order of the interviews, with a view to preserving anonymity and confidentiality.

This study was approved by the Research Ethics Committee of the Federal University of Paraná, from the Department of Health Sciences, according to opinion nº 2,327,633/2017.

Results

Six community health workers, five oral health assistants, five dental surgeons, six nurses, five physicians and six nursing technicians took part in the research. The participants were, on average, 40 years old. In one of the units, there was no participation of oral health professionals, as there was no dental service; and, in another, there was no medical professional at the time of data collection.

The thematic categories that emerged from the statements were: Strengths and weaknesses in the organization of the care of children with special needs; and Infrastructure of services for meeting children with special needs.

Strengths and weaknesses in the organization of the care of children with special needs

Regarding the care of children with special needs, the interviewees pointed out strengths and weaknesses, according to the statements: *When the child is being treated, you end up encompassing the child and the family* (D3). *I perceive the satisfaction of being able to help, I love assisting them, I love doing my job, I really like children* (AB4). *Working with children is even hard, but having a disability is much more* (T2).

The interviewees showed ambiguity in the care of children with special needs, both in terms of understanding the rights of these children and in the interpretation of the principles of equality and equity in the Unified Health System, as evidenced by the statements: *Right to family, housing, right to health care, respect, we all have to have this, regardless of whether it is from the family or society* (D6). *They have priorities in care both in the unit and anywhere* (AC3). *We'll not move a child who has decreased mobility to come here unnecessarily* (M4). *You try to be more sensitive, but it ends up being a consultation like any other* (M3). *Priority, you arrive and await, as you shouldn't skip the line. It does not exist* (T2).

Regarding family adherence and participation in the follow-up of children with special needs, the surveyed professionals reported that: *Commonly, mothers who have a special child, they already know everything* (E4). *The family should take part in everything, and its members should know how to deal with it, how to act and guide the child or the person who has a problem* (AB2). *These children with disabilities, they don't come to us, that's why we have to go after them* (AC6).

Infrastructure of services for caring for children with special needs

Despite reporting the effort to care for children with special needs in the best possible way, the interviewees recognized limitations in the organization of services, such as the absence of specific protocols, the need for training professionals, an environment little prepared to serve this audience, as well as shortage of materials and inputs available. *I think we don't have a certain guidance on what to do when a disabled child arrives* (M6). *We, as a professionals, try to give the best of ourselves, try to give more attention* (M3). *We had some things during college, but nothing like that specific to the city focused on work. I think it'd be cool if it had* (M5). *Here, at the health unit, we have no structure or material to assist children with disabilities* (D1). *We don't have access covers, the street is horrible, it's not just the unit, it's the entire location of our coverage area, it's not an easily accessible place* (E3).

In the interviewees' statements, we perceived the relationship between the organization of the Health Care Network to which children are referred and the improvement in the development of children who use services provided by the network: *It is already included in a service that is the school, which already has a psychologist, besides specialized teachers* (AC2). *The network operates like that, it is the Social Work Reference Center, the Health Unit, the Psychosocial Care Center, the Specialized Social Work Reference Center, the schools, the Municipal Early Childhood Centers, it is all linked; therefore, when there is a child who needs something, they are directly linked to the network* (AC4). *Primary care, specialist and rehabilitation, when the three things work right, it's when we reach the best outcome* (M5).

Discussion

The data were represented by the reality of only six Health Units of the same town; however, in order to capture the adversity of context, two units from different districts were chosen, taking into account limitations of the study, thereby not being possible to generalize the findings. Future surveys, with a larger sample size, are relevant to give continuity to the results of this study.

Primary Health Care professionals reported difficulties in meeting and dealing with the care of families of children with special needs. The key points for integral care are the experiences that health professionals receive(7), including at the phase of welcoming, characterized as humanized care that allows people access to services(3).

In the speeches of the professionals who took part in this research, the low demand of families in relation to the services in the Health Unit was mentioned. In addition, it was mentioned that the health services need to search for these children, which may be related to the pertinent literature that shows low credibility of families for the care of these children in Primary Health Care(11).

We emphasize that the bond between the multiprofessional team and the family should start at the first home visit(7), after the childbirth, thereby taking advantage of the moments of follow-up to strengthen the trust in the team and the relationship of care humanization(3).

The interviewees recognized that children with special needs have the same rights as others, which demonstrates the knowledge of the concept of equality. Nevertheless, with different needs, in order to have the right to be fully treated, they need differentiated support, whether through training of professionals to serve them, ambience or adequate infrastructure. Moreover, the interviewees revealed that, among the team members, there is no uniformity in the knowledge about the rights of these children.

In disagreement with one of the statements, which depicted that there is no priority for care, there is a rule that establishes the establishment, articulation and expansion of health care points for people with disabilities in the Unified Health System. The Care Network for People with Disabilities ensures equity in the care of people with disabilities(12). Among the guidelines, for the operation of this network, we can highlight the promotion of equity and the assurance of integral access to quality services, with multidisciplinary and interdisciplinary assistance, humanized care and focused on the people's needs(13).

The way in which public policies improve children's well-being and physical integrity is by providing access to information about rights and aid programs(14). Accordingly, in order to enable the families of children with special needs to be aware of these rights, the support of health professionals becomes necessary for contributing to the quality of life of these children and for implementing public policies in an effective way(11).

The interviewees demonstrated great expectation that families would coordinate child care. Families and health professionals are responsible for assistance and care guidelines to improve the situation of these children(7). Health services should allow families to share difficulties and, adequately, understand their weaknesses(5). Several stages of care are required and recognized as emotional tension and stress; therefore, it is necessary for health professionals to understand and ensure integral support to the families of children with special needs(15).

Basing the speeches of the professionals, referring to the orientations, it is important to maintain communication between the team and the families, with qualified listening, since the support of information may reduce the negative impact of the diagnosis of disability. Faced with several failures in the structure and organization of the Health Care Networks, families still deal with difficulties in access, in the resolution of health services and in the continuity of treatment of children, which are often the factors that discourage the search for assistance in Primary Health Care(11).

In the organization of the care of children with special needs, limitations were expressed in the statements, such as the absence of specific protocols for care, little preparation of the team and lack of training. The speeches also indicated obstacles, such as the inadequacy of existing services to meet the needs of children and their families in the territory.

The Primary Health Care service has a weak profile, thereby interfering with the quality of care, which may be one of the causes of the low insertion of these children in health services(11). There is unpreparedness for the care of children with special needs due to the lack of training and education of professionals in relation to this topic (4). The care directed to children is also the responsibility of Primary Health Care; therefore, the professionals of these teams need to be able to ensure quality and resolutive assistance(11).

The managerial sector of the Health Units is responsible for providing support to the teams and carrying out permanent health education, with a view to offering adequate assistance to children with special needs(5). The professional qualification in health should be in accordance with the needs found for assistance(16).

The establishment of decent work for health professionals in the scope of Primary Health Care becomes effective in meeting the health needs of people with disabilities in a multidisciplinary context(16). With the provision of training, there is an adequate assurance of access to health care for all people, thereby improving results, considering and respecting the rights and needs of the population in general(8).

Even with the implementation of decentralization policies, we still need a more effective and comprehensive measure to achieve a more equitable scenario(17). The expansion and the qualification of the offer of services in the territory and the coordination of care are essential attributes for integral assistance in Primary Health Care(1).

It is necessary that Primary Health Care professionals have training and qualification, thereby ensuring safety in care. It is considered relevant for professionals to know the public policies that regulate the actions to be held(3); therefore, it is important to foster qualified professionals to work in the Health Units(18).

The co-responsibility of other professionals for following-up children with special needs in the Health Care Networks, being an intersectoral and interdisciplinary action, with a view to providing quality of care, emerged in the interviewees' statements. It also emerged that multiprofessional action is essential for investigating the solution of health problems. For people with disabilities, rehabilitation entails health promotion, since the achievement of autonomy and the victory over limitations tend to provide better quality of life for people and families(3).

Primary Health Care professionals are responsible for the early detection of warning signs in the development of children with special needs, in addition to following-up and conducting the appropriate referral of children to specialized and reference services, when necessary(2).

The care demands of children with special needs and families are wide enough to be met only in Primary Health Care. Therefore, the expansion of the coordination of care, in order to integrate health services and programs to these children, is crucial for reaching good results. Children should have access to prevention, promotion, therapy and rehabilitation services(9). The strategy of matrix support is fundamental, since it facilitates the diagnostic clarifications, as well as the organization of actions(19).

A model of collective work, intersectoral teamwork, establishes articulation and mutual influence among professionals, with skills and practices. The way in which professionals get involved and interact with each other has an influence on the work routine. With the purpose of providing integral health care, collaboration is strengthened, aiming at articulating various specialties, in order to overcome the fragmentation of work and assistance(3).

When a team or matrix support professional shares knowledge with the reference Family Health Strategy, the matrix support helps the team in the organization and accomplishment of a therapeutic project for a subject, individual or collective, who needs health intervention, where the reference team may also present difficulties during its performance. The organization of the system in the Health Care Network has a relevant role, where the Family Health Care Center teams are extremely important to ensure the full right to health of children with special needs and their families(19).

Health professionals should advise and guide families about the children's referrals to the Health Care Network services, thereby encouraging them to share any concerns that they may have, as well as ensuring the continuity of care in Primary Health Care(20).

In order to contribute to a broad vision regarding the work objective, it is essential that the purposes of health services are aligned, so that everyone can manage and use elements that enable an integrated team, thereby making the network effective through the interprofessionality(2).

Conclusion

This study has demonstrated that the organization of Primary Health Care to provide care to children with special needs and their families, from the perspective of the health team, expresses ambiguity and unpreparedness of services in relation to the rights of these children, in the qualification of the team, as well as in the requirement for specific protocols to standardize this service. We can consider that these services, when organized and articulated with the Health Care Network to meet these families, may ensure access to health services with quality and equity, which may provide improvement in the health conditions of these children.

Collaborations

Schuertz AL, Mazza VA, Seidel B and Ruthes VBTNM contributed to the conception, design, analysis, interpretation of data and writing of the manuscript. Macedo LC collaborated with a relevant critical review of the intellectual content and final approval of the version to be published.

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