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CHILDREN WITH DIABETES *MELLITUS* TYPE 1: VULNERABILITY, CARE AND ACCESS TO HEALTH

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ABSTRACT

Objective: to investigate the trajectory and follow-up of the health of children with diabetes *mellitus* type 1 in regard to the attention given by the different public health services and the relationships between the services, the child and their families, from the perspective of mothers and caregivers.

Method: qualitative study with inductive thematic analysis, based on the theoretical references of vulnerability and health care networks, from in-depth interviews with 56 mothers or caregivers, in two Brazilian public health services.

Results: reports marked by sufferings, challenges and notes show the centrality in the disease, fragile access, little resolution, insecurity in urgent and emergency situations and superficial bond with insufficient support to the family, and fragmentation. The specialized care is characterized by trust, the bond and the efforts to prevent the use of other health services.

Conclusion: families and children are exposed to vulnerable circumstances in the longitudinal follow-up, with consequent distancing of network care. Thus, they indicate the need to expand the integration of care, intersectoral actions, social participation and coordination of care networks, in search of greater access and inclusion. Therefore, there are implications with political and financial efforts to advance access to comprehensive care and reduce vulnerabilities.

DESCRIPTORS: Child. Diabetes *mellitus* type 1. Health care. Chronic disease. Health vulnerability.

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CRIANÇAS COM DIABETES *MELLITUS* TIPO 1: VULNERABILIDADE, CUIDADO E ACESSO À SAÚDE

RESUMO

Objetivo: investigar a trajetória e seguimento da saúde de crianças com diabetes *mellitus* tipo 1 no que concerne à atenção prestada pelos diferentes serviços públicos de saúde e as relações entre os serviços, a criança e suas famílias, na perspectiva de mães e cuidadores.

Método: estudo qualitativo com análise temática indutiva, baseado nos referenciais teóricos da vulnerabilidade e redes de atenção à saúde, a partir de entrevistas em profundidade com 56 mães ou cuidadores, em dois serviços públicos de saúde brasileiros.

Resultados: relatos marcados por sofrimentos, desafios e apontamentos mostram a centralidade na doença, o acesso frágil, pouco resolutivo, a insegurança nas situações de urgência e de emergência, o vínculo superficial com insuficiente amparo à família, ea fragmentação. A atenção especializada é caracterizada pela confiança, pelo vínculo e pelos esforços para evitar a utilização de outros serviços de saúde.

Conclusão: as famílias e crianças estão expostas à circunstâncias vulneráveis no seguimento longitudinal, com conseqüente distanciamento do cuidado em rede. Assim, indicam a necessidade de ampliar a integração dos cuidados, as ações intersetoriais, a participação social e a coordenação das redes de atenção, em busca de maior acesso e inclusão. Portanto, há implicações com esforços políticos e financeiros para avanços no acesso ao cuidado integral e redução de vulnerabilidades.

DESCRIPTORIOS: Criança. Diabetes *mellitus* tipo 1. Atenção à saúde. Doença crônica. Vulnerabilidade em saúde.

NIÑOS CON DIABETES *MELLITUS* TIPO 1: VULNERABILIDAD, CUIDADO Y ACCESO A LA SALUD

RESUMEN

Objetivo: investigar la trayectoria y seguimiento de la salud de niños con diabetes *mellitus* tipo 1 en lo que concierne a la atención prestada por los diferentes servicios públicos de salud y las relaciones entre los servicios, el niño y sus familias, en la perspectiva de madres y cuidadores.

Método: estudio cualitativo con análisis temático inductivo, basado en los referenciales teóricos de la vulnerabilidad y redes de atención a la salud, a partir de entrevistas en profundidad con 56 madres o cuidadores, en dos servicios públicos de salud brasileños.

Resultados: relatos marcados por sufrimientos, desafíos y apuntes muestran la centralidad en la enfermedad, el acceso frágil, poco resolutivo, la inseguridad en las situaciones de urgencia y de emergencia y el vínculo superficial con insuficiente amparo a la familia, la fragmentación. La atención especializada se caracteriza por la confianza, el vínculo y los esfuerzos para evitar la utilización de otros servicios de salud.

Conclusión: las familias y los niños están expuestos a circunstancias vulnerables en el seguimiento longitudinal, con conseqüente distanciamiento del cuidado en red. Así, indican la necesidad de ampliar la integración de los cuidados, las acciones intersectoriales, la participación social y la coordinación de las redes de atención, en busca de mayor acceso e inclusión. Por lo tanto, hay implicaciones con esfuerzos políticos y financieros para avances en el acceso al cuidado integral y reducción de vulnerabilidades.

DESCRIPTORIOS: Niño. Diabetes *mellitus* tipo 1. Atención a la salud. Enfermedad crónica. Vulnerabilidad en salud

INTRODUCTION

The growing expansion of chronic conditions, both in developed countries and in developing, triggers crisis in the health care system, which is aimed predominantly reactive, episodic and fragmented way, to chronic disease exacerbations events.¹⁻² The Diabetes Mellitus type 1 (DM1) is of particular importance and 5% to 10% of all diabetic patients in Brazil are children or teenagers.³

The longitudinal follow-up of children can bring many health benefits together with the increase of strategies for reception, health surveillance and disease management in health services and in families.⁴ The continuous attention is of extreme importance in the silent moments of the aggravations when chronic conditions evolve insidiously; it is necessary a health model that builds and sustains the completeness, interdisciplinary and intersectoral approach, considering the needs of the population with a view to the resolution.¹

The traditional biomedical models of health care are inefficient in the face of the complexity of chronic conditions^{2,5} with a compromise completeness of health care, which can generate situations of vulnerability.^{2,6-7} The use of health services involves complex aspects, with dimensions regarding the needs, demands, offer of actions and health services.⁸

In this context, it is important to emphasize that in Brazil, the Health Care Networks (*Redes de Atenção à Saúde* – RAS in portuguese) are in the process of being implemented, which constitute polyarchic organizations of health services linked to each other and towards a single mission, offering continuous care and integral, in which Primary Health Care (PHC) is the coordinator. In addition, the Brazilian Ministry of Health defined as one of the priority care lines to care for people with chronic conditions, based on risk stratification, decision support, clinical information system and self-care.^{6,9} The entire implementation process is a major challenge, marked by gaps in the continuing education of health professionals, in the management of health care under chronic conditions, and in resistance related to disruption with the traditional model.⁵

Considering the relevance of investigating the use of care resources,⁸ the challenges in the health care of children with DM1,¹⁰ network care,^{1,6,9} the complexity of chronic conditions^{6,9} and rethinking the issues of comprehensive and longitudinal care to the child with DM1,¹¹ becomes relevant the trajectory and the follow-up of the health of these children in different health services.

This study assumes that, in the view of mothers and/or caregivers, there are gaps in care and fragmentation in the organization of health care for children with DM1, with difficulties in communication and integration between different health services. Thus, the objective of the present study consisted in investigating the health trajectory and follow-up of children with Type 1 Diabetes *Mellitus*, regarding the care provided by different public health services and the relationships between services, children and their families, from the perspective of mothers and caregivers.

METHOD

Qualitative study, based on the conceptual framework of vulnerability,¹² health¹³ and network care.^{1,6,9}

The construction of the conceptual framework of vulnerability in the health field is recent and is related to preventive actions and possibilities of moving beyond practices strictly supported in biomedical knowledge.¹² Its premise is that people face different situations of vulnerability, individually or collectively, and situations of aggravation or threat to health can be particularized by the recognition of three interconnected dimensions: the individual, the social and the programmatic or institutional.^{12,14} Such dimensions should not be analyzed in isolation, but rather captured in their singularities, pointing

out the vulnerability of whom, the vulnerability to what, and the vulnerability under which circumstances or conditions.¹²

Still, health care is understood as the search for a health care based on dialogic, i.e. based on the knowledge and values of the different subjects involved and on the meanings and practical meanings of their goals, demands and interventions in the health field.¹³

Priority care lines and network care for people with chronic conditions depart from the idea of reducing people to their illnesses and propose collaborative and person-centred attention instead of prescriptive and disease-centred attention. The proposal is based on welcoming, dignity, respect, empathy, trust and self-care supported, with a relationship between users and health professionals.^{6,9}

The research was developed in a Brazilian city, located in the state of Minas Gerais, in the outpatient clinics that meet the local and regional demand for diabetes in the Municipal Center for Diabetes Care (MCDC) and in the Pediatric Outpatient Clinic of the university hospital, called in this study specialized outpatient clinics.

The study was conducted with children with DM1 who were being followed up in public health services in 2013. According to cadastral data collected in July 2013, a total of 84 children under 12 years of age with a medical diagnosis of DM1 were followed up at one of the two specialized public clinics residing in the city. Of these children, 24 were concomitantly attending private services and were enrolled in the public service only for the receipt of medicines and materials for children with DM1. Of the 60 remaining children, one did not agree to participate in the study, and three were not found and were not present at the time of data collection. Thus, 56 mothers and/or caregivers responsible for children with DM1 participated in the study.

The data collection was conducted through open and in-depth interviews, which were recorded in a reserved space in the waiting rooms of the selected health services, lasting from 40 minutes to one hour. The following trigger question was used: "How has your child's care been in public health services since the discovery of Diabetes *Mellitus*?". During the interview, there was a dialogue about the difficulties of attending to the public health services, difficulties or facilities to access services and encouraging reports of everyday situations related to follow-up the health of the child with DM1, with attention to access and interaction with the public health services.

The data analysis was performed based on the inductive thematic approach, in which the identified themes were extracted from the data themselves, based on repetitive readings, identification of significant situations, considering the objectives of the study and subsequent grouping in thematic units, not fixed *to priori*, i.e. they were based on the data itself.¹⁵ The themes were seized seeking the articulation between them and the deepening, relating and reflecting on the theoretical framework.

It should be mentioned that no computer programs were used to manage the data. It was used the Consolidated Criteria for Reporting Qualitative Research - COREQ¹⁶ as criterion for data organization, being codified in 11 items: lack of qualified professionals; access difficulties; fragmentation of care/lack of communication among health services; trust in specialized outpatient clinics; insecurity in other services (basic care and prompt care); inadequate care in basic care services and prompt care; superficial linkage of specialized outpatient clinics; unprepared professionals in the care of children with diabetes; situations where participants' knowledge has been underestimated; excessive bureaucracy; need for humanization and agility.

The study respected the ethical principles of research involving human beings in accordance with Resolution 466/2012 of the National Health Council. For the anonymity and confidentiality of the data, for the identification of the interviewees, the letter E was initially used, followed by the Arabic number, according to the order of interviews. The informed term of consent was delivered in two copies to each participant, and only after reading and clarification was signed by those who agreed

to participate. It was guaranteed the freedom of spontaneous participation and the right to withdraw at any time from the research.

RESULTS

Of the 56 study participants, 46 were mothers, eight were parents and two grandparents, aged between 18 and 61 years. In relation to the children, 29 of them were male and 27 female; ten were under 5 years of age, 16 were between six and nine years and 30 were between ten and 11 years, 11 months and 29 days. The average period for defining the diagnosis of DM1 of these children was three years and nine months, with a minimum diagnosis time of two months and a maximum of ten years.

The results emerged from the systematization of qualitative data, in a process of apprehension of meanings about the trajectory in the public health services for the follow up of children with DM1, from the perspective of the mothers and/or caregivers, who derived the following thematic units: Insecurities, reception and trust in public health services; access, linkage and (dis)continuity in the health care of the child; organization of local health services and institutional vulnerability.

Insecurities, reception and trust in public health services

There is a predominance of related reports, particularly with urgency and emergency situations in the emergency care units. The reported situations suggest that there are inadequacies in the health care of the child with DM1, with negative consequences to the family. Such a context weakens relations with health services in terms of safety and trust, with decision making of no longer using them. Participants mentioned that prompt care recognizes their incipience when recommending that they seek the DM specialist.

Saying that is... [first-aid] is all difficult. If I take there they will ask to take him to the diabetes doctor. I do not trust. They have no notion there. I take care of her [daughter] at home, but I do not take her there, except when she disagrees (E52/mother).

I feel insecure to take him to the first-aid because a situation has happened: one day he [son] got sick, I took him and I told that he was diabetic, and the doctor asked to give serum with glucose, then the nurse went to give and I said she could not because he was diabetic. I only take him if it is really necessary and I'll always be close to see it all. I'm scared to death that I cannot be around. In the first-aid, if I need, I get insecure. I'm afraid because I took him several times and they said 'calm mother, he has nothing'. And he was already with diabetes, it was until he went into a coma (E32/mother).

The difficulty of communication in health institutions and the lack of professional qualification constitute a scenario of vulnerability and insecurity, in this case for the group of children with chronic conditions and their families.

The child's follow-up in basic care is also perceived by the participants as fragile, with impacts on childcare. In this sense, the reports point to disregard and identify certain professional attitudes as contrary to health and human rights.

He does not do that kind of childcare there [health center], because after diabetes was discovered I do not take him there because it causes a lot of confusion (E9/mother).

You arrive at a health center and you are poorly served by something you are not asking please. (E56/father).

In contrast, relations with specialized outpatient clinics are characterized as reliable and welcoming, in the specificity of DM1 pathology.

I think I've got confidence here [specialized outpatient clinics]. It is good when we trust the doctor we go, it's good to go to a person you already know. I trust a lot here. Because it already happened that I took her to the [first-aid] and they did not assist because she was diabetic and they said she needed a referral from where she was being treated for them to assist her, and I had to bring her here. Then, when I got here, the glucose was altered and she was hospitalized (E22/mother).

I was even impressed with the care for the diabetics here [specialized outpatient clinics], because we were very well attended, we were very well received. So it has a very big difference, they are opposites [referring to the primary care service] (E56/father).

In this context, it should be emphasized that the units of basic health care present communication difficulties with the specialized services and, in the view of the participants of this study, with deficiencies in training and empowerment of health professionals in dealing with the health of children with chronic conditions. These aspects point to a culture of excessive trust in specialized services, which makes it difficult the follow-up of the child with DM1 in the primary health services, reinforcing a situation of institutional vulnerability.

The study participants present situations that can be resolved in basic health care, and which portray the need for greater clarification and reception in the attention of the health of children with DM1. They mention aspects of the difficulties for scheduling appointments and obtaining prescriptions, as well as facing the periods of DM1 decompensation. Furthermore, they are unaware of how childcare can be integrated into the follow-up at the specialized outpatient clinic.

Schedule and consult I find it very difficult [specialized outpatient clinic], because for us to be able to make an appointment we have to call after the 20th and sometimes, when we can make an appointment it is more than a month late because there is no vacancy (E36/mother).

He consulted here and I thought that here [specialized outpatient clinic] everything was solved. Only after they said I had to take him to the pediatrician as well. Communication is lacking (E21/mother).

I call and if there is a vacancy I already make an appointment [specialized outpatient clinic]. You have to wait to open his schedule [doctor]. It is only difficult when he is on vacation, when he is returning there is a complication of full schedule, that is difficult. Or when you have a period that is full. My daughter stayed two months without consultation because of this. Also, if I need an emergency consultation, there is no way to do it. If her glucose is deregulated, I have to wait to schedule, wait to open the agenda to schedule (E42/mother).

The aspects mentioned here about insecurity and the establishment of confidence suggest that the adjustment of services to the health needs of children and their families is fundamental in order to increase the follow-up and care of children with DM1.

Access, bonding and (dis)continuity in child health care

There is a strong link with outpatient clinics specialized in endocrine-pediatrics, despite indications of fragility in terms of access, especially in situations where the therapeutic regimen and glycemic control are not fully established.

I asked the doctor: 'If I need an urgent care, how do I do it?' He [doctor] asked me to take her... [first-aid] when it is more directly related to diabetes (E42/mother).

Twice I needed urgent care and there in the... [specialized outpatient clinic] there was no doctor. Once she was [child] feeling a lot of pain in her belly and with that strong odor of ketone, this right at the beginning, and there was no vacancy, not even a fit. And the other time was in the exchange of insulin, because it was rising a lot [the blood glucose] and we did not know what to do. I tried to talk on the phone and I could not, it was difficult, it took a while. I gave up because I called there about four times (E52/mother).

The aspects mentioned are dissonant to the interest and the concern of the mothers or relatives in obtaining information and orientations in the search of comprehensive care to the child with DM1. Thus, signal the little involvement of health services and professionals in the care guidelines related to daily life, being the central focus in control of DM1. These situations generate solitude in the caring process, in which mothers or caregivers recognize in themselves the effort to address the demands of child care with DM1.

Regarding the child care guidelines, referring to hygiene, sleep, safety, has no guidance at all. I know because I research a lot. We are really alone. There was a female doctor [doctor] who set up a group and taught to do a carbohydrate count, but it was only her. Then she left and now we do not have it anymore (E3/mother).

The treatment of the diabetic is not only insulin and medication, but also guidance. Because, for example, my daughter is ashamed to say she has diabetes. So, if there was a better education, a group that could help, a team, because not only a doctor is enough, it is not enough for the nutritionist to help count the carbohydrates (E546/mother).

The linkage with specialized outpatient clinics and the distance from basic health care units can lead to a deficiency in the child's health care, depriving families of rights, care, follow-up and important information.

Among the specificities of the care of the child with DM1, the participants highlight the vaccination, when they say that the specialized service does not care about it and they refer the responsibility to basic health care.

The lack of information regarding details such as, for example, vaccines. The first year I gave the vaccine I learned from the mothers that I had to bring a report. When I arrived to give it, they said I had to bring another special document. Then there is a lack of communication between health services (E21/mother).

I bring all her things, but I did not bring the vaccination record card today. I do not bring the vaccination record card because they [specialized outpatient clinic] do not ask it. In fact, they only require the diabetes control device. But, vaccination record card, usually they [specialized outpatient clinic] do not say anything, so I do not bring (E29/mother).

These aspects mentioned by the participants point to situations which touches on the principle of longitudinality and raise possibilities of discontinuity and incipience of the quality of health actions, as well as, can determine difficulties in the care of children with DM1.

Organization of local health services and the institutional vulnerability

The participants' reports raise concerns about the organization of local health services. In order to increase the follow-up of children with DM1, they emphasize the need for more specialized,

qualified, differentiated, humanized and more agile care. They recommend a single place of reference, with breadth of access and coherent behaviors.

Having a place of reference for the care of the diabetic would be ideal, because as there is no structure to receive in case of crisis, even the doctor [in the specialized outpatient clinic] does not have the time, does not have availability to be attending in case of emergency. It is humanly impossible because he is already overloaded and does not have an appropriate physical structure to receive. In the first-aid there is no professional prepared to deal with diabetes (E2/father).

I think it should change a lot, people also have to be more human. It should be just one place to attend, because every place you go you have to be talking, explaining. If it were in one place would be good (E20/father).

It would be great if it were all in one place, I would not have to run. For example, vaccine has to go there in the health center, care has to come here [specialized outpatient clinic], consultation here, urgency in the first-aid. So, It is run to and fro. If it were all in one place would only be better (E43/mother).

There are also suggestions for improvements specifically in terms of human resources, they said that greater security can be guaranteed with the possibility of a telephone on duty, having home visits and greater specificity in the care and monitoring of the child and his family.

It would be nice if there was service by phone, especially in the beginning, because I had a hard time dealing with her diabetes. Not today, I'm easy, I already know what is happening and what can happen. But it would be very good, especially at the beginning of the diagnosis, because we are very frightened, we have never seen it, she has had a seizure, she has bit her tongue, she has stuck her mouth and it is very difficult (E39/mother).

The health service had to go in the houses, had to give an orientation, had to have a work to help people, because often people do not even know what to do (E17/mother).

Another note refers to health education actions for the child and as support for the family.

Be created a group to help children. On vacation, when the social worker [specialized outpatient clinic] takes the children to the park, she [daughter] goes at one o'clock and I get her at five o'clock. That week is great, the dextro [glucose test] of her gets controlled, it's wonderful. They learn to control themselves among them. So, if there is a way to educate... The government is able, if it wanted to do it, it would. At school she does not go well, she passes to another grade because the teachers help her, she is depressed and not always father and mother can help. Lack education regarding diabetes, the doctor may be great, but it is needed to add a section to help in diabetes education. These days she came to her father and said: 'father, which day am I going to die?' We cannot convey all the necessary information to her, so if there was a group to guide, it would help a lot. (E46/mother).

The reports express the need to expand the environments, strategies and policies for the care of children with DM1 and their families.

DISCUSSION

The trajectory of health care revealed by mothers and/or caregivers of children with DM1 is marked by suffering, challenges and centralization in specialized care, characterized by the efforts

of families to avoid the use of other health services. The reported situations show elements of the health care model for children with DM1 in the municipality in question, where there is a predominance of care for acute conditions, with inefficiency of referral and counter-referral mechanisms that result in redundant and disarticulated actions. Few actions of basic health care have been mentioned, suggesting that they are undervalued and not differentiated from the set of actions recommended for the longitudinal follow-up of the child's health.

Considering that the RAS constitute spaces that defines and consolidate completeness, in search of resolution and attendance to the needs and health problems of children and the population, in their different moments of the life cycle,¹ it is possible to affirm that the aspects reported for the municipal reality investigated reflect the crisis in the health systems, which generally indicate a fragmented and organized health care in isolated points of attention and without communication with each other, with difficulties to effect the continuity of health actions, particularly for the chronic conditions.

In the perception of the people who use the health system, fragmentation is expressed as lack of access to services, loss of continuity of care, lack of coherence between the actions of the services provided and the population's health needs and their overcoming have been a great challenge in several countries.¹ These elements are in agreement with notes of health agencies in the context of chronic diseases and constitute obstacles to network care.¹

Thus, for the effectiveness of network care, the participation and empowerment of PHC services are extremely important in order to organize and coordinate care.^{6,9}

An investigation carried out with professionals in the scope of PHC about the problem of children with chronic disease concluded that, given the increase in the occurrence of chronic conditions, health services must transpose organizational proposals aimed at the treatment of acute problems and the longitudinal care should be valued.¹⁷ The results of the present study point to actions of the health services in line with the traditional biomedical model and important disconformity with the models of attention to people with chronic diseases in RAS, Promoted by the current health policies in the country^{6,9} and a similar result was found in another study.⁵

The chronic conditions in children reveal themselves as promoters of complex care.¹⁸ The present study reveals situations of distancing from the concept of health care, which imply intersubjective relationships, with the sense of encounter and the act of placing yourself before another person, meaning possibilities and sharing.¹³

In the contexts of intersubjective relationships, a qualitative study with people with DM found that the relationship of individuals with health professionals and services often starts from an authoritarian and terrifying perspective.¹⁹

A Scottish study indicates that the parents of children with DM1 are inhibited by the presence of the child in the consultations and omit important information. In addition, they present anxiety, worry and fear of being reprimanded by health professionals, in relation to glycemic control of their children, with important consequences in the assimilation of information and, in extreme cases, omission of relevant information.²⁰

A review on the health care of children with diabetes has pointed, from the user's perspective, to the value of services that have been involved with social aspects and that have been sensitive to the broader context of their lives and not just their bodies. From the perspective of the parents, the need for safety and resolutiveness in relation to health services was reported, similarly to the present study.²¹

The care taken by the health services has a widely impact on the life of the child patients with chronic condition in which the child's role¹⁸ and the creation of support networks^{18,22} need to be

incorporated. Thus, the relation with the health services is influenced by elements of the trajectory and the familiar experience of the chronic condition.²³

Health professionals should have active postures and leave the context of the prescription and enter into that of the interactions with strengthening of the capacity of listening and understanding of the situations experienced by the individuals, in search of comprehensive health care. It is important to consider that the contexts of intersubjectivities, knowledge and representations constructed in social interactions have a cumulative effect and impact on self-care and healthy behaviors.²⁴ In this direction, health education practices characterized by vertical knowledge, guided by the unilateral provision of information, must be transformed into reflexive spaces with qualified listening, exchange of experiences and valorization of knowledge. The care with the child with chronic condition must be singular and humanized. It is necessary to listen to the child and make it the protagonist of his therapeutic plan, considering his opinions and perceptions in the construction of an extended care.²⁵

The concept of vulnerability is configured as a dynamic of reciprocal interdependencies that express multidimensional existential and social values, leading to forms of exclusion, segregation and denial of rights.²⁶ In this direction, children and their families, in the current reality, are in situations of vulnerability due to weaknesses in PHC, seen as an organizer of RAS, as well as the difficulty of accessing health care actions and facing problems when they need care emergency without reference, with poor organization and communication between services.

The assistance gaps show the component of institutional vulnerability, which, in turn, interfaces with the individual and social components.¹² Institutional vulnerability brings together the degree and the quality of commitment of services, resources, management and monitoring of national, regional or local programs and guidelines for prevention, promotion, treatment and longitudinal follow-up, which are relevant to identify the needs and existing resources and to optimize their use,¹² in favor of children and their families. In addition, many users rely on systems because they believe that their health records are shared among microsystems and are less active when they perceive that their contribution is undervalued.²⁷

Difficulties and negative experiences lead families not to “take any risks” in the search for other health services, other than endocrine-pediatric outpatient clinics, even in emergency situations, seeking, whenever possible, the achievement of well-being at home or in specialized services. It indicates, therefore, vulnerabilities by individual, collective and contextual aspects, with more or less availability of protection resources.

A qualitative study with caregivers of children with chronic conditions verified the insecurity regarding child care by other people or institutions; they believed only in their ability to care for the child, overwhelming and strongly impacting her life.²⁸

Part of the vulnerabilities identified in this study is related to centralized care actions in specialized services, with implications in the principle of completeness. There are obstacles that hamper the consolidation of this principle, both in the actions of professionals, in identifying the health needs of people, and in various political, cultural and structural aspects of health services and society itself. In addition, the centralization of care in a single service can unleash gaps to act resolutely in different dimensions, which favors fragmentation and represents difficulties for the effectiveness of RAS.²⁹

Nevertheless, the context that constitutes a centrality in the medical professional brings gaps, linked to the trend, to specialist medical training, hospital and sophisticated technologies and unrelated to the needs of the health system.³⁰ The confrontation of this problem runs through the resource enterprises and pro-coordination strategies of care,²⁹ with the performance of the APS to the effectiveness of the integration throughout the user's route in the network.

The commitment of completeness and coordination of care also occurs in other local health systems, which present low interprofessional communication and lack of information technologies.³¹ The communication between family health professionals and professionals from other specialties has not evolved in recent years, which shows that family health professionals believe that access to other specialists is poor or acceptable and vice versa.³² In addition, in a micro context, it is important to emphasize that health professionals need to improve their communication, empathy, and emotional support skills in handling children with DM1.³³

In order to improve communication between the services, studies show successful experiences with computerization and with a single database.³¹ Thus, coordination of care permeates the attributes of PHC and is also related to the determinants of municipal systems and the macro-structural organization of the RAS.³¹ In this context, the poor coordination of health care and the communication failures compromise the safety of care and many errors occur due to the difficulty of communication between health services,²⁶ compromising extended and comprehensive health care. In addition, PHC needs to be more into line with the model of attention to chronic conditions proposed by the Brazilian Ministry of Health.²⁸

The Social, political, and structural determinants have a greater contribution to health than biological factors and personal choices. Thus, harmful interactions of health conditions and adverse structural and political circumstances become synergistic in the context of chronic health conditions. The fight against inequalities that mainly affect vulnerable groups is a major challenge for health services in Brazil and in the world.³⁴

In the context of children with DM1, the challenges faced by health services are many, as well as by families. The universal access to health services is a major challenge for management, with the need to effectively analyze the numerous barriers that hinder access to health,³⁵ being important the interinstitutional articulation, the reorganization of the entry point into the system and the overcoming of weaknesses to guarantee access.³⁶ Another important challenge in the implementation of RAS is the distance that exists between the formulation of proposals and policies and their effective realization.³⁷ The action through focal programs was expanded throughout the existence of Brazilian public health system (Sistema Único de Saúde – SUS, in Portuguese), a typical fragmentation of Brazilian public health.³⁶ In addition, for the federal office, the challenge of governing regions and states with hundreds of different health programs remained.³⁸

All chronic diseases are characterized by stable periods and punctuated by exacerbations and it is extremely relevant to fill gaps between health actions and services, avoiding frailties, difficulties, accidents and errors.³² Initiatives to monitor the quality of health results are extremely important to ensure that people in vulnerable situations receive a care with effective and equitable cost³⁹ to deal with the effects of deprivation, inequities and the knowledge of potentialities, weaknesses and challenges. It is important to emphasize that the health care system for children with chronic conditions needs to be networked, emphasizing the needs of intersectoral relations¹⁸ in the micro and macro dimensions of health systems, with a view to law, citizenship, social justice and improvement of living conditions.⁴⁰

Therefore, for the transformation of the structural determinants of SUS, it is important to strengthen political and social processes,⁴⁰ the integration of care, the social participation, the collaboration and coordination of RAS.⁴¹

In this direction, the political and financial efforts are needed to avoid the synergistic interactions of chronic diseases with the determinants of the disease process,^{42–43} for advances in access to comprehensive care and reduction of vulnerabilities.

The results of this study are limited to the population studied and make it impossible to generalize to other contexts and populations. In addition, the study was limited to the child population

and to families that exclusively used public health services. However, the particularities of such situations increase the understanding of care and of the interfaces with health services and their institutional vulnerabilities. It is important to conduct more studies in different settings and populations, with observation of the care offered by health professionals and management instances, in order to overcome the challenges in the care of children and to accomplish the implementation of RAS in the context of the health of the child with DM1.

CONCLUSION

The reports are marked by situations that reveal suffering and challenges. In addition, they revealed weaknesses in the attention to the health of the child with DM1 evidenced by the identification of the vulnerable points: approach focused mainly on pathology, fragile and unsuccessful access, insecurity due to situations that demand urgency and emergency, superficial attachment, poor communication and insufficient support to the family, configuring characteristic of the traditional biomedical model, besides aspects of discontinuity of care and violation of rights.

The search for well-being and relief from suffering comes from the efforts of the family, who are reluctant to seek other health services other than specialized outpatient clinics.

The interviewees also pointed out some elements that facilitate the follow-up of the health of children with DM1 in specialized services: trust in specialized outpatient clinics, recognition of specialized and skilled care, and differentiated knowledge of the disease. This context configures the fragmentation of RAS marked by insecurities in relation to PHC services and prompt care and assistance focused on specialized services. It has revealed a distancing, with models of health policies for people with chronic health conditions prevailing in the country.

Health actions with incipience of targeting, fragmented and disorganized do not lead to effective resolution and is necessary to enable, optimize and reorganize individual, social and institutional resources. By recognizing the importance of effective communication between health services, presence and coordination by PHC in the care of children with DM1, the RAS guidelines can contribute and offer relevant solutions.

The focus on the concepts of vulnerability, health care and network and its interfaces with the individual and social dimensions bring contributions to rethink health practices, with subsidies for the reorganization of care, regarding the management of DM1. Thus, it is important to incorporate new instruments and knowledge that reduce vulnerability and allow support and a repertoire of orientations to mothers and guardians in an expanded, constant and networked way.

It is important to strengthen the political processes, the planning, the communication, the collaboration, the professional training and the monitoring at micro and macro levels of health systems.

In the perceived reports, the nursing professionals were not specifically mentioned in a spontaneous or emphasized form. New research may examine the efforts of these professionals in the care of children with chronic conditions from the point of view of network care, as well as explore issues of family and community singularities and care in exacerbations, urgencies and emergencies derived from DM1.

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NOTES

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ETHICS COMMITTEE IN RESEARCH

Approved by the Ethics Committee in Research with Human Beings of the *Escola de Enfermagem de Ribeirão Preto, Universidade de São Paulo*, N. 405818 Certificate of Presentation for Ethical Appreciation (CAAE): 09258813.8.0000.5393

CONFLICT OF INTEREST

No any conflict of interest.

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