



RESEARCH ARTICLE

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RIGHTS AND SOCIAL SUPPORT TO FAMILIES OF CHILDREN WITH AUTISM SPECTRUM DISORDERS: AN INTERVIEW WITH BRAZILIAN MOTHERS

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ABSTRACT

Background: The child with autism spectrum disorders has problems with socialization and coexistence. The lack of knowledge about the problem and the difficulties that families and institutions face in dealing with inclusion do not help the development and coexistence in society. Inclusion is not simple, because it requires specialized and accessible care. **Objective:** This study aimed to analyze the perception of the mothers of children with autism spectrum disorders on the social support received, in order to promote a reflection on the guarantee of human rights. **Methods:** This is narrative research, cross-sectional qualitative. An unstructured interview applied to 20 mothers of children with autism spectrum disorders, followed by a health service and residents of a Brazilian city. The interviews to analyze by the Method of Meaning Interpretation, based on dialectical hermeneutic principles. **Results:** It was found that, in general, the participants reported that they like to live in the city, mainly because they are close to their relatives. They reported dissatisfaction with issues related to leisure and safety, and with schools, pointing out that these spaces are not prepared to review their children. As for the benefits received and affordability, they should not be so. It can be seen that these families have few opportunities for effective access to inclusive services. Civil society and the government need to hear these families. **Conclusions:** Families of children with autism spectrum disorders need greater social participation in communities in order to claim accessible spaces and the realization of the rights to the city and health that everyone deserves.

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INTRODUCTION

The World Health Organization (WHO) describes disability a result of interaction between a person with some kind of impairment and the environment, creating limitations (WHO, 2001). Included in such profile are those individuals bearing limiting or impairing motor, functional, behavioral, emotional and/or developmental conditions. With regard to children with disabilities, these demand continuous special care, whether temporary or permanent, depending on a multiplicity of special

services, both healthcare-related and social services. Services that go beyond those which were commonly required by children without disabilities. Resources that should be available and accessible, which need to carry out in the home environment by their caregivers (Neves, 2008). Urban areas, in terms of availability and access to services, generally regarded as better than rural areas. In many situations, the opportunity to live in areas with better access to electricity, running water, paved roads, nearby schools and hospitals may indeed be very tempting (Gautam, 2013). However, with respect to the

families of children with an autism spectrum disorder, this is often a necessary choice in an attempt to keep them healthy, especially if these families depend on public services. The importance of the family in social interaction is recognized. Its role as a mediator of the relations with the community constitutes an effective social solidarity network in taking care of the health of its members (Figueiredo, 2016). Nevertheless, keeping the family members active and confident in the role of care has been a challenge, as it implies an articulation between society and access to favorable public policies. Understanding and caring for health in the biological aspect is fundamental but, beyond that, articulation with the social, cultural and economic determinants is necessary, in order to expand the chances of better results. The child's autism spectrum disorder can fragment the parent's sense of capability and reliability, slowly giving rise to a deep wound that can take a long time to heal. The family seeks to adapt to a new reality and reorganize itself in order to face the experience of living and cohabiting with the disabled family member, in an effort to rebuild the family group's identity. Such a situation often involves feelings of vulnerability and requires an emotional readjustment, which demands time (Barbieri, 2016). Being a parent of a disabled child initially generates a period of shock, followed by sorrow or anxiety, and then the acceptance of the child gradually occurs (Guerra, 2015 and Milbrath, 2010).

One resource to help these families represented by the sources of social support, which transcend the space of professional and family relations. Satisfaction with the social support and with the father/mother role, good family functioning, father/mother-child affective bonding, spousal support, and the feeling of actively participating in social life can contribute to reducing stress levels. Through the hindrance, parents should be encouraged to seek care for their needs, to adapt with reduced difficulty to the new routine of care, also aiming for an improvement in the quality of family bonds (Ribeiro, 2013 and Fiamenghi, 2007). Regarding the concept of social support, there is little consensus in the literature and the present article adopted the definition proposed by Gottlieb and Bergen (Gottlieb, 2010), which regards as social resources those that are perceived by people or actually available to them, whether those are conducted and provided by professionals or not. It is understood that the necessary relationships established between people, and often between them and institutions, are set in a dynamic and complex process with a strong potential to promote improvements in people's quality of life. Social support can be represented by five dimensions, namely material, emotional and effective support, positive interaction, and information (Chor, 2001), and can be believed according to its formal or informal nature. Formal support includes formal social organizations, such as hospitals, health services, government programs, and professionals, which organized to provide assistance or support to people facing personal and social fragility. Informal support encompasses individuals with whom there is emotional and effective closeness, such as family, friends, spouse, neighbors or colleagues, and social groups, which are capable of providing support to the activities of daily living, and in the places where they live (Dunst, 2009). In the literature that social participation and strong social support open the way for access and guarantee of rights, positively influencing family life. In this context, was social support, received and perceived by the mothers of children with autism spectrum disorders and living in a Brazilian city, able to ensure and expand the social rights and accessibility of children? This question guided the

present research. Thus, this article aims to analyze the perception of the mothers of children with autism spectrum disorders about the social support received, in order to promote a reflection on the guarantee of rights. The analysis of such elements within the city space will provide support for the implementation of local actions, services, and policies.

MATERIALS AND METHODS

This is narrative research, cross-sectional qualitative. The qualitative research was chosen because it is able to approach the interpretation of daily life and the experiences of the participants. However, the limitations implied in this choice will influence the reproducibility of the findings of this study in other populations. The researchers' present hands-on experience with children with autism spectrum disorders, one of whom works at the health service where the children go. This researcher invited the participants, participated in the analysis of the information but did not conduct the interviews so as not to influence the participants. The real concern to expand the possibilities of support and guarantee of the rights of this population motivated the elaboration of the present research. Inclusion criteria were women aged over 18 years, mothers of children with autism spectrum disorders followed at the Pediatric Rehabilitation Unit of a Health Center located in the municipality of Patrocínio, Minas Gerais. This health unit serves almost 82 children. Intentionally, all the mothers who followed their children at the chosen health service were invited, 62 did not agree to participate. Thus, the sample resulted in 20 mothers.

Data collection began in December 2016 and ended in December 2017. This study was submitted to the Ethics Committee in Research with Human Beings of the University of Franca. Approved under CAAE 62623416.9.0000.5495. Used the SRQR reporting guidelines (O'Brien, 2014). The interviews were recorded on the cell phone and transcribed by the researcher shortly after. This study considered only the interviews with information about social support perceived by study participants. For the reliability of the information, the recordings were checked in pairs, comparing the written part of the narratives with the recordings. For the validation of the results, the categorization of the information was discussed and agreed upon among the study researchers. The information from these interviews was analyzed according to the Method of Meaning Interpretation. This qualitative method based on dialectical hermeneutic principles. The theoretical-methodological reference of the hermeneutic-dialectical perspective used, seeking to understand the reality situated in its context, linked to the critical confrontation of the problem to be studied. While hermeneutics emphasizes the meaning of what is consensual in the unity of meaning, dialectics is oriented to differences, contrast and therefore to criticism.

Patient and Public Involvement: The non-structured interview used, starting with the question: After the diagnosis of your child, how was the family's support?

On the day scheduled with the mothers, the researcher went to the home of each family to request the signing of the Informed Consent Form and to conduct the interview. The confidentiality of the participants was preserved by placing the letter F followed by Arabic numerals (F1, F2, etc.). The results were presented at the study site. Two meetings were held, one with the mothers, and the other with the workers and

management of the health service. The interviews divided a priori into two categories of analysis: Influence of social support and; Rights and accessibility (Minayo, 2014 and Gomes, 2014).

RESULTS AND DISCUSSION

In all participating, the mothers represented the families. The majority were married, aged between 31 and 45 years, eight years of schooling, low family income, and no paid work.

Influence of social support: The role of the city as the support network stands out as fundamental in the development of a child with a disability. The actions conducted by the professionals are focused on the learning of development strategies, the potentialities of the person with special needs, and their relationship with the world. Such actions prove essential for the families' experience. It is known that the birth of a child with a disability modifies the entire family structure. There is a surprise, shock, or fear of the unknown. In addition to the family as a unit, each member will be required to adapt to the new situation individually (Barbosa, 2019). This is when the issue of social inclusion will become a part of everyday family life. It is known that formal networks coexist with informal networks, although sometimes not recognized by professionals, pointing out the need to value the user and their networks as protagonists in the search for the support that is not always initiated in the basic health care services. Support provided by informal support networks includes family members, friends, neighbors, colleagues, and social groups. The formal support network encompasses professionals and institutions formally organized to assist those in need (Maximino, 2017 and Brandão, 2011). The synergy of these networks that the family of a child with the disorder has been determining factors for the improvement of quality and the normalization of their lifestyle. The development of studies in the field of education and defense of human rights has been changing concepts, legislation and pedagogical and management practices, promoting the restructuring of regular and special education in Brazil. The reinterpretation of educational inclusion in these precepts may promote the elimination of barriers that impede access to school (Brandão, 2011). As for this statement, the participants have demonstrated dissatisfaction with the educational support offered to children with special needs. Several families report that the municipality should make more professionals available in the area of education and offer a better infrastructure at schools and daycare centers for those children who need special and particular attention:

[...] I think there should be better-qualified professionals. The schools, whether public or private, are not well prepared. They accept but do not know how to work (F11).

[...] He needs a learning support teacher and adapted materials. [...] The school should already be prepared to receive special students (F17).

The professionals point out difficulties in activating the formal network in the face of complex living. Recognize individual initiatives and the creation of internal support networks can facilitate their actions (Maximino, 2017). Adding the knowledge of the physical activity, healthy eating, and health promotion may be able to produce positive effects on teachers'

knowledge, and simple and low-cost educational actions may represent the first step in motivating health promotion actions, resulting in personal, social and economic benefits to all those involved in the school community (Sousa, 2012). It can, therefore, be inferred that training teachers on the needs of children with autism spectrum disorders could also be the first alternative to sensitize these professionals so that they act consciously towards the inclusion and health promotion of children with disabilities. In caring for a disabled child, it is necessary to consider the needs of the children, who, when observed, listened to, and respected, can give important clues about the quality of what they are receiving. Care procedures also need to follow the principles of health promotion. On the educational activities offered at the schools, the participating families showed deep dissatisfaction with the activities directed at children with special needs. Due to the absence of inclusive actions in the school environment, in disagreement with the laws on disabled children's rights, which state that every child is entitled to participate in activities intended for children, regardless of diagnosis and social class:

[...] There is a lot of talk about inclusion, but there is no such inclusion [...] Whenever he attends a gymkhana at school, he has left aside... because there is no activity intended for him (F12).

[...] The school does not have didactic material adapted for him. If the school accepts special children, it should be prepared, and they pretend that nothing is happening (F3).

Inclusion is an innovation, whose meaning was very distorted, and a movement made very controversial by the most varied educational and social segments. However, inserting in the regular education students with deficits of all nature, whether permanent or temporary, more or less severe, means nothing beyond guaranteeing everyone's right to education. The embracement of the special needs of the child at school reassures the family, enabling greater confidence in the school and the implementation of further activities possibly less stressful and emotionally draining. In the present study, the families report difficulties in finding school places, since all children with special needs have the right to be in regular schools and to have a life equal to those of children without disabilities:

[...] We are satisfied with the school, you know. Lately, it has been doing more for her (F8).

[...] But it was very difficult to find a place ... [...] they thought he would go into convulsions ... Now in kindergarten, they have realized that he was not going into any of that. He became well adapted at school and to his classmates as well. I'm very much calmer (F4).

It is incumbent upon all professionals working in special schools, special classes, and study support rooms for children with an autism spectrum disorder or special needs. Upon inclusive education theorists, regular school professionals and multidisciplinary and health teams, the primary function of action integration, resource and service optimization, creation of communication channels that regard the issue of social inclusion as a priority, and preceding the school inclusion. The educational environment is not the only one where professionals and schools are required to comply with the

appropriate settings in order to meet the needs of persons with disabilities (Sharts-Hopko, 2020). Given that, regardless of the professional sector, it is always necessary to bring to the center the users, their rights, and the limits and potentialities of their social places. It is necessary to reinvent resources and connections in the meeting between institutions and individuals, which affect each other and can support networked care practices (Maximino, 2017). Fernandes et al (Fernandes, 2011) found that family routines such as conversations at different times can promote emotional bonds and bring about favorable consequences to the mental health of children with special needs. Such routines demand energy and effort from the parents, being liable to experience barriers and difficulties in relation to the routine and support for the children's leisure, as reported by families F12, F8 and F7:

[...] with regard to leisure time, public activities, we face difficulties because they never conduct activities aimed at those who have physical disabilities (F12).

[...] There should be outdoor games, a play area, with green, with animals (F8).

[...] On the weekends, we went out looking for alternatives because here there aren't any. He likes to go to small squares that the city hall has built [...] but the toys there are not adapted. How am I going to get him to play on the slide? or put him on a swing? (F7).

It is extremely important to support and empower parents to take a more proactive stance towards the development of encouragement to the modifications needed to improve the child's quality of life (Grubb, 2016). Issues related to public safety in the city were among the families' concerns, as mothers reported that, when walking more slowly with their children, due to their limitations, they felt more vulnerable to the risks of being approached on public roads. Public safety is the removal, by means of its own organizations, of any danger or harm that may affect the public order, to the detriment of the life, liberty or property rights of each citizen. Brazilian public security is limited to individual freedom, establishing that every citizen's freedom, even to do anything that is not forbidden by law, cannot disturb the freedom assured to others (Madeira, 2015).

The participants of the present study were disappointed with regard to the security and accessibility offered in the municipality where they reside:

[...] When we arrive at the parking lot, there is an unidentified common car in the disabled parking space. People do not respect the disabled persons. [...] there are no security officers watching over that (F1).

[...] The passengers themselves spoil that place which is reserved for the special child to stay [...] I've never taken a bus that had the safety belt available for use in his seat (F13).

The lack of security and accessibility, however, as it exists in every society and in all human relations, it is therefore also present in all social classes. Not too long ago, the majority of the world's population lived in predominantly rural areas. Such reality has been changing over the last decades, and people have been increasingly residing in urban areas (United

Nations Department of Economic Social Affairs/Population Division, 2015). Most families were dissatisfied with the support that the municipality makes available for the daily life of their children in terms of leisure, health care and social support and, among others, it is important to highlight the need for strategies that collaborate on the city development process and offer support to these families.

Rights and accessibility

When the focus is on human rights, a concept taken as a basis is the one discussed by authors regarding this process as the product of the relationship between the effective availability of health services and the access that these individuals with special needs have to the inclusive services. Individuals with special needs have the right to access and inclusive services under the laws of Brazil. However, the participating families reported difficulties in accessing the necessary rights their children lack, regarding accessibility issues and the benefits offered by the government:

[...] Everything I need, I have to go like a beggar, chasing it, and despite the statements, and there in the statute of the child, that they are entitled to health, they have the right to be cared for with more dignity (F9).

[...] My son fitted into the welfare benefit of the disabled person. It was such a fight to get that, a fight indeed. It should not be like that (F13).

Thus, the notion of rights as often applied to persons with autism spectrum disorders, and particularly in the area of social rights, often discussed in terms of justice and rarely, of freedom. Such a framework has led to the inadequate implementation of the concept of rights of persons with disabilities and has unforeseen consequences, including the ways in which they are considered in the formulation and achievements from the perspective of the civil rights (United Nations Department of Economic Social Affairs/Population Division, 2015), as concerning the rights to mobility in urban spaces, for instance. In Brazil, the accessibility of persons with disabilities or with reduced mobility, before the obstacles on public roads, at schools, in the construction and renovation of buildings, and in means of transport and communication, is guaranteed by law in accordance with article one of Law No. 10,098 (United Nations Department of Economic Social Affairs/Population Division, 2004). As the local governments reach greater participation and knowledge of the real needs of the population, they refine decisions about the city in which they want to live, helping each other to move towards health equity. In this scenario, the right to health closely related to the right to the city, as it will reduce inequalities and expand the use of the positive effects of urbanization to delayed and disadvantaged groups (Figueiredo, 2017). The families reported that the benefits and accessibility offered by the municipality where they live are scarce, given that, according to the statements, many conditions should be improved:

[...] I've never got any help related to means of transportation, not a penny to help with the costs of his treatment. Where is the disabled person's right? (F14).

[...] Accessibility? [...] it has to improve a lot (F10).

The lack of support from the health services is an obstacle to the diagnosis, treatment, and recovery of children and

adolescents with special needs. There were several situations in which families felt neglected by the health services, such as the lack of clarification about the diagnosis, the lack of orientation by the professionals and the lack of activities specifically aimed at children with disabilities, corroborating with Barbieri's study (Barbieri, 2016). According to these reports, one can perceive that children with autism spectrum disorders attest to our human frailty expose the inadequacy of our cities, the inoperability of our legislation and our accommodation to what must modify. These elements upset and divide us.

Conclusions

Social support for families of children with disabilities is substantial for the link between families and society, reducing inequalities of opportunities, access and effective availability of inclusive services. In order to guarantee rights acquired in city spaces, it is pertinent that, in the social context, the formulation of actions to support children with autism spectrum disorders should plan and implement health care that considers not only the needs of the child but also the family for the relief of suffering and stress. It is necessary to expand and consolidate these spaces of social participation of families as important instances for the achievement of accessible spaces and guarantee the rights to the city and health that everyone deserves.

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