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Social network and support in care for children with Down Syndrome

Rede e apoio social no cuidado de crianças com Síndrome de Down

Red y apoyo social en el cuidado de niños con Síndrome de Down

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ABSTRACT

Objective: to describe the social networks of caregivers of children with Down Syndrome and the type of support they received. **Method:** in this qualitative, descriptive study, framed by Sanicola's methodology, interviews were analyzed using Bardin content analysis. The research protocol was approved by the research ethics committee. **Results:** the social networks of the caregivers interviewed were predominantly small, not very dense, and featured strong relationships with family and friends. From analysis of the interviews, three categories were identified: emotional support from the family; emotional and financial support from friends; and dissatisfaction with the health service. **Final remarks:** it is necessary that health personnel, particularly nurses, address the subject in order to discover the relationships and how they are established, so as to strengthen bonds and carry out interventions to improve quality of life for caregivers of children with Down Syndrome.

Descriptors: Nurses; Down Syndrome; Caregivers; Social Network.

RESUMO

Objetivo: descrever a rede social e o tipo de apoio recebido por cuidadores de crianças com Síndrome de Down. **Método:** estudo descritivo com abordagem qualitativa com base no referencial metodológico de Sanicola. Para análise das entrevistas utilizou-se a técnica de análise de conteúdo de Bardin. Protocolo de pesquisa aprovado pelo Comitê de Ética em Pesquisa. **Resultados:** as redes sociais dos cuidadores entrevistados são predominantemente pequenas, pouco densas, marcadas por fortes relações com familiares e amigos. Na análise das falas foram identificadas três categorias: apoio emocional da família, suporte emocional e financeiro dos amigos e insatisfação com o serviço de saúde. **Considerações finais:** a abordagem da temática pelo profissional de saúde, principalmente o enfermeiro, faz-se necessária para o conhecimento das relações e como elas se estabelecem, de forma a fortalecer vínculos e realizar intervenções que visem uma melhor qualidade de vida para os cuidadores de crianças com Síndrome de Down.

Descritores: Enfermeiras e Enfermeiros; Síndrome de Down; Cuidadores; Rede Social.

RESUMEN

Objetivo: describir la red social y el tipo de apoyo que reciben los cuidadores de niños con Síndrome de Down. **Método:** estudio descriptivo con enfoque cualitativo con base en el marco metodológico de Sanicola. Para analizar las entrevistas se utilizó la técnica de análisis de contenido de Bardin. Protocolo de investigación aprobado por el Comité de Ética en Investigación. **Resultados:** las redes sociales de los cuidadores entrevistados son predominantemente pequeñas, poco densas, marcadas por fuertes relaciones con familiares y amigos. En el análisis de los discursos, se identificaron tres categorías: apoyo emocional de la familia, apoyo emocional y económico de los amigos e insatisfacción con el servicio de salud. **Consideraciones finales:** el enfoque del tema por parte del profesional de la salud, especialmente del enfermero, se vuelve necesario para conocer las relaciones y cómo estas se establecen, con el fin de fortalecer vínculos y realizar intervenciones dirigidas a una mejor calidad de vida de los cuidadores de niños con Síndrome de Down.

Descriptores: Enfermeras y Enfermeros; Síndrome de Down; Cuidadores; Red social.

INTRODUCTION

Down Syndrome (DS), also known as Trisomy 21, is one of the most common chromosomal genetic alterations in humans and is the main cause of intellectual disability in the population. The presence of a third chromosome 21 in the genetic material is responsible for determining specific physical characteristics, in addition to developmental delay[1,2].

The main characteristics of DS are cognitive impairment, hypotonia, weight and height deficit, psychomotor deficit, brachycephaly, straight and thin hair, excess adipose tissue on the back of the neck, and ligament laxity, among others. In addition, individuals who are born with this syndrome are more likely to develop health changes such as vision and hearing problems, heart and gastrointestinal tract malformations, diabetes and thyroid dysfunction[1,3].

It is estimated that there are around 6 to 8 million people with DS in the world and an incidence (without major worldwide variations) of one case in every 700 to 800 pregnancies[4].

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The multidisciplinary follow-up of children with Down Syndrome is essential for their cognitive development and social interaction. Thus, health professionals need to have knowledge of adequate care strategies to conduct interventions in the biopsychosocial dimensions of the child and family[5].

In this perspective, the nursing team can help during the adaptation process of caregivers to the diagnosis through monitoring, support and guidance from the beginning, developing strategies which can bring more security and preparation for the family to live with and take care of the bearer of the syndrome. It is necessary that the nursing team has technical and human knowledge to implement these strategies, which in turn enables providing complete and quality care[5].

Primary healthcare (PHC) is the gateway to the health system for the population, and is one of the main partners in the process of embracing children with DS and their caregivers, as it is capable of organizing the services necessary to care for this population group and contribute to promote their healthy development. In addition, PHC can ensure interaction and participation of members of the social network of the person with DS in care[6].

Networks can be understood as a system composed of several social objects, meaning people, functions and situations which offer instrumental and emotional support to the person in their different needs. Some resources are necessary for the successful adaptation by the child with DS and their caregiver, such as intra-family and extra-family support from friends (primary network), and from institutions and health professionals (secondary network). These supports form part of the family's support network which the family resorts to when there is a need[7].

The social supports received and perceived by people are essential for maintaining mental health, coping with stressful situations, relieving physical and mental stress, as well as promoting beneficial effects on physiological processes. Thus, there is no doubt about the benefits of a social network for families with members with some type of disability, and in particular for those with children with DS[7].

A study carried out with special patients in Aracaju, Brazil, points to the burden of primary caregivers of children and adolescents with DS. The study was composed of a group of 84 caregivers of children/adolescents with DS and a control group of 84 caregivers of children and adolescents without disabilities, and it was possible to identify that the absence of or little burden was predominant in the control group (89.2%), while 72.6% of caregivers in the study group had moderate burden[8].

Other studies indicate that caring for a child with DS impairs the family's privacy and consumes time and energy, causing a social, emotional, psychological and financial burden, and that this burden may be related to the family's feeling of uncertainty about the future and the consequences of this care on their lives[9,10].

One study points out the importance of the nurse's role in humanely embracing families, as it is possible to strengthen their resilience and facilitate the adaptation process in the face of obstacles that arise[11] by considering them in all care dimensions and providing guidance on the necessary care for children with DS.

In this sense, this study is justified by the need to understand how the social network of caregivers of children with DS is configured and the support they receive to deal with difficulties during the care process. There are few studies directed to this theme and caring for those who care is essential to preserve the well-being of the caregiver and consequently make them more willing and proactive to deal with the process.

Given the above, the following guiding question emerged: How is the social network of caregivers of children with DS constituted and what kind of support does this network offer to families for the care of children with DS?

The study object was the network and social support configuration of caregivers of children with Down Syndrome, and the established objectives were to describe the social network of caregivers of children with Down Syndrome, and to identify the type of support received by caregivers in providing care of children with Down syndrome.

METHOD

This is a descriptive study with a qualitative approach based on the theoretical-methodological framework of Sanicola[12], in which the social network is understood as a set of links, harmonious or not, established between the members that compose it. It can be primary when composed of family, friends, colleagues or neighbors, and secondary when expressed by the individual's relationship with professionals from non-governmental organizations, the workplace and public and private institutions focused on social assistance, health, education, religiosity or solidarity. In addition, social support is defined as a type of positive support that members of the social network offer, whether material, financial, emotional and/or psychological. Moreover, the bonds established with network members can be classified as strong, normal, fragile, conflicting or broken[13].

The study setting was a Municipal Rehabilitation Center in the city of Rio de Janeiro. The study participants were five caregivers of children with Down Syndrome living in the city of Rio de Janeiro. In order to meet the inclusion criteria, the participant had to be the primary caregiver of a child with DS who was being attended at the aforementioned Rehabilitation Center at the time of the data collection period. Those who had any psychiatric and/or intellectual limitations that would hinder full understanding of the questions were excluded from the study.

Data collection took place from January to June 2020 through a semi-structured interview. The study objectives were presented at the beginning of the collection, the Informed Consent Form (ICF) was read and a document was requested to participate in the study.

The first part of the interview consisted of filling out a form to characterize the socioeconomic profile of the participants, and a script with guiding questions was used for the second part to create a map of the caregivers' social network, according to the theoretical-methodological framework of Sanicola[12].

In this step, the following questions were asked: *Tell me who the people are who are present in your life and what kind of bond you have with them. At some point did you need help or did you have any difficulty taking care of the child who was diagnosed with Down Syndrome? What kind of support do you receive or did you receive?*

The interviews were conducted individually in reserved places, lasting from 15 to 30 minutes and recorded with the aid of a recorder and cell phone.

The pandemic scenario of the disease caused by the type 2 coronavirus (COVID-19), which was present from March 2020, required restrictive measures such as social distancing, and therefore one of the interviews took place through a form online from Google, and it was not possible to map the social network of this interviewee in person.

All statements were fully transcribed and a thematic analysis of their contents was performed. Bardin's content analysis technique was used as a reference for this analysis, which consists of coding the data, aggregating them into record units, which can be a word, phrase or theme for later categorization, meaning to group elements with common characteristics[14]. The analysis of the social network maps was performed based on the methodological framework of Sanicola[15].

The letter C was used to identify the maps and excerpts from the interviews to ensure the anonymity of the participants, followed by a number according to the order in which the interviews were conducted. Thus, the first respondent is represented by C1, the second by C2, and so on.

The research protocol was approved by the Ethics Committee of the institution involved, with the consent of the management of the health unit and approval of the Ethics Committee of the Municipal Health Department of Rio de Janeiro. All study participants signed the Informed Consent Form (ICF) and were assured the rights of anonymity and voluntary participation.

RESULTS AND DISCUSSION

Regarding the profile of the participants (Figure 1), it was noted that the mother was identified as the main caregiver in all cases.

C	Gender	Age of the caregiver	Relationship	Education	Work	Time living together	Religion	Income in Reais (R$)	No. of dependents	Child's age
C1	Female	45	Mother	University	No	1 month	Evangelican	3500.00	5	6 months
C2	Female	38	Mother	High school	No	Since the child was born	Spiritist	2500.00-3000.00	4	10 months
C3	Female	25	Mother	High school	No	Since the child was born	None	1045.00	4	1 year and 4 months
C4	Female	26	Mother	Incomplete high school	No	Since the child was born	None	300.00	3	1 year
C5	Female	41	Mother	-	No	Since the child was born	None	-	3	2 years

FIGURE 1: Characterization of the socioeconomic profile of caregivers of children with Down Syndrome. Rio de Janeiro, RJ, Brazil, 2020.

These mothers were between 25 and 45 years old and did not work outside the home. With regard to education, four mothers attended high school or higher and only one did not finish high school. Family monthly income varied between 300 and 3500 Reais, and the number of dependents in the household ranged from three to five people.

Mothers were primarily responsible for household activities and providing care for children with DS. This reality may be related (among other factors) to beliefs about the female role and motherhood in contemporary industrial societies, which consider women responsible for caring for children and carrying out household chores[7].

When describing their social network, the caregivers reported having a small, not very dense support network, marked by strong relationships with family and friends. The type of relationship with secondary network institutions proved to be normal. In addition, with the testimonies obtained in the interviews, it was possible to verify different types of support received by the primary caregiver and dissatisfaction related to contact with the health services.

As a result, three categories were identified: emotional support from the family, emotional and financial support from friends, and dissatisfaction with the health service.

Emotional support from the family:

In this category, the family constitutes an important source of emotional support, showing interest, acceptance and help, as evidenced by the following statements:

> *"My aunt, my mother, and my sister are more present, these are the people who ask the most about him". (C1)*
>
> *"They took care of M. (child) with as much love as it was with her, there was no reason for prejudice or distance, from the moment I communicated to them about M. and I feel, I see, they are always present." (C2)*

Corroborating these statements, a previous study on the difficulties, facilities and support that parents find in caring for their children with DS points out that the family constitutes a support base, playing an essential role with regard to acceptance, support and active participation in the child's development[16].

C2's speech shows a previous concern related to prejudice and non-acceptance that the child could suffer. Studies have revealed that the impact of the diagnosis and fear of discrimination and prejudice are among the main factors related to parenteral stress in caregivers of children with DS[17].

The stigma and prejudice related to people with Down Syndrome are perpetuated and reach contemporary times, although currently there is more pronounced mobilization regarding their inclusion in the social environment[18].

Emotional and financial support from friends:

In this category, it was possible to observe the help of friends for caregivers of children with DS to face emotional and financial issues:

> *"(Friends) They ask, they treat him like a normal child, if I ask for something and he can do it, he will find a way to help, I know I can count on these people, for me to come here my friend M. stays with the girls, F. (friend) is always asking, before I need it, she gets a donation of something, it helps." (C1)*
>
> *"Sometimes I turn to his godmothers a lot, I'm more one to ask them for help and when they don't have it, they ask me for help, and it's one helping the other. P. helps me a lot. I even paid the Uber to take me to see the Bolsa Familia thing... he is a person I turn to and I know he will help me." (C4)*
>
> *"They pay my bills, go to the market so I don't have to leave the house." (C5)*

A study points to similar results in the social support networks of parents of children with DS, identifying that most of them mentioned extra-family support, mainly from friends. Support coming from beyond family members is related to lower risks of developing stress and depression by parents, successful adaptation, resilience and greater happiness[7].

The speeches in this category demonstrate assistance in care and emotional support received from friends. A study identified that this support helps parents to better deal with the difficulties involved in caring for children with special needs. The speeches of C4 and C5 show the importance of financial support from this network. This same study showed that parents who value their support network have fewer problems related to finances, which may be related to the financial support offered by the extra-family network[19].

It is worth highlighting the speech of C5, which highlights the obstacles of the COVID-19 pandemic scenario experienced at the time of the interview. C5 reports that friends went to the market in her place so that she did not have to leave the house, in addition to providing financial support. This speech refers to the social distancing measures

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necessary to contain the spread of the disease and the socioeconomic, psychological and emotional challenges that caregivers of children with DS face in a pandemic scenario. About 50% of people with Down Syndrome have heart disease and 1 to 10% have hematological disorders, which can impair immunity and make them more susceptible to infections, which can offer a greater risk of developing and worsening COVID-19[20].

Thus, care for children with DS in this context should be increased, which can generate fear, anxiety, stress and overload for caregivers, combined with the financial concerns they may have with the measure of social distancing[21]. Therefore, support from the network of friends becomes essential to minimize the impacts that the pandemic can have on these families.

Dissatisfaction with the health service:

This category refers to the relationship established by caregivers with members of the secondary social network, mainly characterized by health service professionals who provide care to children with DS. In contact with such professionals, lack of attention to early diagnosis, lack of mother interaction in the child's rehabilitation process and poor quality of care in the primary healthcare service were evidenced, as pointed out in the speeches:

> *"They even said he had nothing, can you believe it (...), that they didn't see him sticking out his tongue?" (C1)*
>
> *"So when they found out that she was a child with down syndrome, they didn't even support me, you know? Look, you're going to look for this, you're going to do this. [...] Look, I thought like this... I thought we were going to see what is happening inside (the office), we are kind of distant, you know? We stay here, our children stay there and at the time of delivery it's like a school, delivery and not much happens, unless we ask. I thought it would be more like that, for us to go or teach us to do something at home, the exercises, the motor part, the speech part, right... if there was something for us to continue at home, then I think it's a little far from my point of view." (C2)*
>
> *"It's the worst (bond), they never attend and there's never a doctor." (C3)*
>
> *"I changed the Family Clinic because the one I was at didn't help me at all, not even with his ticket, so I went to my father's area, which is a track." (C4)*

C1's speech and the first part of C2's speech demonstrate the unpreparedness of health professionals when diagnosing DS, especially the lack of guidance. Corroborating this finding, a study carried out with mothers of children with DS identified that they have negative perceptions about the conduct of health professionals when revealing the diagnosis, claiming to have felt helpless and misguided[22].

The second part of C2's speech highlights the fragility of communication between health professionals and the family. A study points out that health professionals have a very important role with the families of children with DS and their actions must be established in the sense of informing and providing clarifications, as well as stimulating a bond with the child, they must act with the objective of strengthening the family for problems. These in turn depend on facilitating actions to understand the situations experienced, and the more clarified they are, the better their commitment and care will be[23].

Within the context of health professionals, the nurse also needs to be able to support families, acting in an empathetic manner and informing about the fundamental care to be implemented with the child, supporting the adaptation and overcoming other difficulties encountered by the family in their day-to-day routines. However, they are still unprepared and/or insecure[24].

With perceptions similar to these findings, the speeches of C3 and C4 address the lack of support from health services. However, considering children with DS, the concept of comprehensiveness disseminated by the Unified Health System (SUS) should be widely used. Thus, professionals working in primary healthcare must be up to date with the various existing protocols and guidelines which direct the healthcare of these children, in addition to being linked to them and their families through the territoriality and proximity of care, acting with an integrated and shared approach, as recommended by the structure of the Healthcare Network (HCNs)[25].

FINAL CONSIDERATIONS

With the present study, it was possible to know the social network configuration of caregivers of children with DS and the importance of the support received in order to face the various obstacles and difficulties that exist in their daily lives.

The primary social network is characterized by family and friends offering emotional and financial support, and significantly favors the physical and mental health of caregivers.

The approach to this theme by the health professional, especially the nurse, is necessary to understand the relationships and how they are established in order to strengthen bonds and carry out interventions aimed at a better quality of life for caregivers.

Thus, the relevance of the social network analysis tool in healthcare is perceived and offers quality care with comprehensive and humanized care to families.

It was possible to notice the need to strengthen the secondary network in the analysis of the maps and the interviewees' speeches. Therefore, it is extremely important that the health professional is recognized as part of the social network of these families, ensuring the follow-up and support of the multidisciplinary team in providing care of the child and also in the care of the caregiver.

In this sense, as a gateway to the public health service, primary healthcare must have an attentive look at families who live with children with Down Syndrome, carry out an active search, constitute a support network and strengthen the bond in order to offer comprehensive and quality care and avoid abandonment of the service.

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