

Support network for families of children and adolescents with visual impairment: strengths and weaknesses

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Abstract *This study aimed to understand the interactions established between social support networks and families that have children and adolescents with visual impairment, in two different cities in the state of Sao Paulo, Brazil. This was a qualitative, descriptive study with symbolic interactionism as a theoretical framework. A genogram, ecomap and semi-structured interviews with 18 families were used. The method adopted for data analysis was narrative analysis. Two themes were found: potentials derived from the relationship with the support network, and counterpoints in the support network. The family members accessed other members of their own family, friends, spiritual and cultural activities, health services, government institutions, and philanthropic organizations as support networks. The weakness in health services support is an obstacle to comprehensive healthcare for children and adolescents living in city A. In city B, other possibilities exist because it has a reference service. Despite the weaknesses in the support network in both cities, the family articulates and develops a foundation so that they can provide the best situation possible for their child or adolescent. It is up to health professionals to provide support to families and empower them to care for their members.*

Key words *Social support, Family nursing, Disabled children, Low vision*

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Introduction

Visual capability can be divided into three functional levels: normal vision, low vision (moderate and severe visual impairment), and blindness. For the individual to be considered visually impaired (VI), specialized medical interventions must not be able to provide him/her with functional vision again¹. Thus, people who have zero or decreased vision, with limits to their daily activities, are classified as visually impaired².

This condition requires constant adjustments, as needs appear in the daily life of the visually impaired and their families. The changes cause family demands that did not exist previously, affecting: intrapersonal and interpersonal relations; activities of daily living; interaction with health care services; and, readjustments in financial, occupational, personal and social levels³. Families of children and adolescents with VI are faced with new responsibilities, and with changing and diverse adaptations⁴.

In order to empower these families to deal with VI, one of the strategies of personal and collective confrontation to be valued and developed is the social support network. This occurs through the ease of suffering, anxiety, and concerns that may develop due to the chronic condition, and actually serves as a foundation for child and youth development

This network refers to the structural and institutional dimension, linked to the individual and his family. Social support is found in the personal dimension, consisting of members of this social network itself, or others that are significant. The types of support described by Sherbourne and Stewart⁵ contain five dimensions: instrumental support, i.e., tangible care; emotional support, i.e., empathy relationships, listening, trust and care; information support, i.e., guidelines and suggestions; emotional support, i.e., affection and love demonstration; and the positive social interaction, i.e., leisure and recreation activities.

Therefore, social support is any information, material aid, social-emotional, resulting in positive behavior⁶. The set of support shared by people in a social context constitutes social network⁷.

In terms of human subjectivity, social support can serve as effective and complete help for some, while for others, this strategy should be complemented by other tools. Thus, there is a need to look at the coexistence of interactions that the family establishes among itself and with society, and how they access support networks and engage with the extended family, neighbor-

hood, church and health care, among others. This thinking facilitates the construction of concrete foundations for the empowerment of families, for overcoming adversity established by the process of childhood and adolescence illness⁸.

This study aimed to understand the interactions established between the social support network for families of children and adolescents with visual impairment, living in two cities in the state of São Paulo, considering the importance of coping with the chronic condition.

Methodology

This was a descriptive study, with a qualitative approach, conducted in two cities (named A and B) in the state of São Paulo. The article is part of a dissertation⁹ that was performed with 18 family members of children and adolescents with VI, as well as their own child or adolescent, totaling 61 participants.

Collection and discussion of the data were performed in light of symbolic interactionism (SI), the theoretical premise that values interaction and makes it possible to understand how individuals understand objects and other people, which guides their behavior in various situations¹⁰.

City A has a 1.137 km² coverage area, with an estimated population of 221,950 inhabitants¹¹. The health network has four hospitals, one is exclusively linked to the Unified Health System (SUS), one provides philanthropic service, and the other two are private. It also has 12 Basic Health Units (UBS), 14 Family Health Strategy centers (ESF), two Psychosocial Care Centers (CAPS), one specialized health center and three Emergency Care Units (UPA)¹². City A does not have a specialized institution to offer specific support to the person with visual impairment. City B has a population of 666,323 inhabitants, with an area of 650.916 km² and 17 hospitals¹³. Of those hospitals, two serve SUS patients, seven provide philanthropic services, and eight are from the private network. The city also has 29 UBS, 17 ESF, five UPA, four CAPS, and four specialized health centers¹³. It has two institutions that support people with visual impairment, and one provides welcoming care services and the other performs actions for global human development, education and social inclusion of people with visual impairment¹⁴.

As a strategy to approach the families, an invitation letter for research participation was

used, given to students with VI. Once the family members responded to the correspondence, we contacted them for scheduling.

Data collection was performed from November of 2014 to July of 2015. First, the genogram and ecomap were developed, which provided the ability to synthesize and provide visibility to ways that the support networks of the child with VI are organized, and to evaluate the family structure, showing who is part of it, the quality of their relationships, and the meanings produced in their context¹⁵. The semi-structured interview followed. Questions concerning the structural and functional evaluation¹⁵ of the family were asked, in addition to the proposal: *Tell me what is / are / the main way(s) to support you and your family access to approach the visual impairment condition of (name of child or adolescent) in your family.*

The interviews were performed mainly in private households of the participants, but also the support institution, respecting the family's availability. Records were then transcribed to allow for progress through the steps of the narrative analysis method: reading and re-reading the interview to establish a central core; disclosure of overall impressions; specification of content focus for the reconstruction of history; and reflective rereading, specifying representative excerpts¹⁶. This referential advocates that the individual, in order to narrate, gives meaning to the experience being reported and, by means of this action, the researcher has access to the cultural process, social action and individual and collective experience¹⁷.

To maintain the confidentiality of the participants, the narratives were identified according to the degree of relatedness the participant had to the member with VI, and the sequence number in which the interview was conducted, followed by the letter A or B, which identifies the city. Children or adolescents were identified by the index case (IC). All statements had structural corrections, without changing the meaning of what was expressed by the interviewer. The brackets [...] indicate two sentences within one statement.

The development of the study followed the 466/12 Resolution of the National Council on Health¹⁸. It was approved by the Research Ethics Committee of the Federal University of São Carlos, with protocol number 422494. Participants received clarification about the information contained in the Terms of Free and Informed Consent form, and the Terms of Assent (for those under 18), both of which were signed by the participants and researcher.

Results

Characteristics of participants

Of the 61 participants who were part of the 18 families, 38 were female and 23 were male. Individuals from eleven families from city A, and seven from city B, participated. The degrees of relatedness of the 61 representatives were: mothers (16), siblings (14), ICs (13), uncles/aunts (5), parents (5), grandparents (3), cousins (2), stepfathers (2) and father's work supervisor (1).

The 18 interviewed families had 21 children and adolescents with VI; three of them have two members with disabilities; of these only 13 participated in the interview - five were participating in school activities, and three did not feel the desire to interact during the interview, and continued playing. Of all children and adolescents, fourteen were male and seven female, aged from four to seventeen, and, the most prevalent age group was the one from ten to fifteen years of age (14). All participants studied, two participants worked in informal services, and two received disability compensation from the National Institute of Social Security (INSS). The causes of low vision were diverse, with congenital cataract (4) and toxoplasmosis (3) being more frequent.

Regarding the health care of members with VI, in city A, seven used UBS, two used private assistance and two used both; in city B, five used UBS only, one used private assistance, and one used both. It was found that four families had another chronic condition in the family core, in addition to IV, and the sequelae of cerebrovascular accident (CVA) was the most prevalent.

The analysis of speech allowed for the understanding of two themes: potentialities derived from the relationship with the support network and counterpoints in support networks. The support accessed by the family was family and friends, spiritual and cultural activities, health care services, and biomedical governmental and philanthropic institutions that support care for the person with VI.

Potentialities derived from the relationship with the support network

Finding support in the family and in the extended network is a remarkable experience in the daily lives of these children and adolescents with VI. The support provided through the close relationship of trust, with the establishment of emotional, affective and instrumental support. Fam-

ily support has been seen as a foundation for facilitating care that children and adolescents with VI demand. It is constituted of reciprocal links, where not only the members with VI benefit, but the whole family, which is structured and empowered through its own in terms of exchange, care, and monitoring.

The whole family helps a lot [...] I have them all, to help us with doctors, exams ... (Mother 5-A).

Friends are also considered an important source of support for children and adolescents with VI and their families. They provide affective and emotional support, information and positive social interactions. The actions performed by friends reflect on self-esteem and existential questions of family, preventing and alleviating prejudices.

The person who helped me most with this problem (VI) was my friend (friend's name). [...] He is a great friend. [...] Wednesdays, Fridays and Sundays, when we meet in the church, we sat beside each other and when it ends we stay there gossiping (IC 4-A).

Cultural activities such as theater and music are a strong support since limitations are overcome and social interaction opportunities increase. In addition, there is concern that the potentialities and dreams may be the same as any other child and adolescent. This minimizes the differences and increases the acceptance and respect. Among the activities that are sources of socialization and distraction, technological resources such as the computer and the use of social networks are also present.

The first time I played, the smile came up here. [...] One day I played at school, [...] my colleagues started to fool around and called me 'guitarist'. After that no one mocks me, I was friends with everyone again (IC 4-A).

Spirituality and religiosity were highlighted as important aspects that weave support. The churches provide not only the approach to God, which seemed to expand the feeling of acceptance and hope to believe in something better for the future of children and adolescents with VI, but also the approach function among members of the community; they help each other through the emotional and material support, serving as a social institution.

[...] We choose the gospel, read a message, a prayer. [...] It is important because if it had not I do not know where we would get support (Sister 2.1-A).

I participate in the church, [...] the support is as follows: 'You will get, will improve, it will im-

prove!' [...] You see people praying for you, helping you, looking at you, calling you, wondering how he is [...] (Mother 1-B).

Counterpoints in support networks of cities

The institutions mentioned in the interviews were primarily those related to health, education, and others, which were added to institutions devoted to the development of children and adolescents with VI.

Health Services

City A

The lack of health service support is an obstacle for the diagnosis, treatment and rehabilitation of children and adolescents with VI living in city A. There were several situations in which the family felt neglected by health services, among which were: difficulty accessing public service; extended wait for scheduled appointments; distance of the doctor from the population; professional-family relationship permeated by prejudice during the sessions; scarce human resources in health services; lack of resolution; prolonged diagnosis; lack of clarification of the diagnosis' ways to stimulate the child; and, uncertainty of the origin of visual impairment and treatment.

The doctor at the Basic Health Unit (UBS) said that all blacks had yellow eyes [...]. I said, 'he (IC) has yellow eyes because he is sick, he has a, eye problem, it isn't because he is black!' [...] (Grandmother 3-A).

We had a SUS appointment [...] it takes 3 to 4 months to get an appointment with the ophthalmologist (Mother 6-A).

The monitoring of children and adolescents with VI in several different city health services, without any communication network or reference and counter-reference system, was also cited as a complicating aspect; it does not allow for a connection between the services, or continuity of care.

When we managed to find care in the city where we were directed to, I think there was some control (of the progression of low vision). But we were confused because they gave a different information about the boy everywhere we went to (Uncle 1-A).

In order to meet the health demands of the members with VI, the family appeals to the private health system, which also has several problems, such as unavailability of short-term consultation, prolonged time for diagnosis, or inadequate communication with family members.

When the doctor looked at (IC name), who would not stay still, he could not examine him and I would have to sign a consent form. I denied. I explained that he was a child, how could I make him be quiet with a still eye? [...] I found the doctor very ignorant [...]. Then I went with a good doctor [...] she anesthetized him to take the exams [...] but she did not say what he had. (Mother 4-A)

City B

Unlike the families of city A, in city B there is an offer of other possibilities, which are permeated by speed and resolution, which can be justified by presenting a referral service, which is not always efficient for families, therefore some seek private services.

At birth, he was diagnosed at the hospital, I did the follow-up during the whole pregnancy, he was born and they placed him on a table and did all kind of examination that he needed [...] when he was one year old he had one eye operated and then the other [...] (Mother 4-B).

In the health services of both cities the actions have a biological focus, oriented only for eye health, without one of the principles established by SUS, integrality. The failures were related to inadequate communication being established with the family, and incomplete information on the diagnosis of the members with VI. However, at the same time in the reference service, the professional approach is welcoming and sometimes has the establishment of effective communication.

At the time (the diagnosis) I just cried and said, what can I do with a blind child? [...] It was all very sudden, very heavy [...] When she was operating we had prepared, it was all day, we joked, talked, she explained to me a number of things (Mother 5-B).

Despite city B offering a specialized SUS service, there was no concern for or connection with therapeutic resources devoted to the social, educational and cultural rights of children and adolescents with VI. None of the interviewed families reported referral for health services to the institution specialized in caring for people with VI in the city.

The institution that attends IC is a blessing; I had never heard of or known where it was. I was met in the hospital by a student who attended the institution, she said, "do not cry, you will go to the institution that supports visually impaired people, at the school I attend. If she becomes blind she will learn everything, I'll give you the address." [...] (Mother 5-B).

Specialized institution

City B

The institutional role as a support network is remarkable. There is an appreciation of the institution and not having to pay for it. The actions of the professionals are focused on learning development strategies, on the person's capabilities with VI, and his/her relationship with the world. In addition to all the specific activities that the institution provides, it performs a direct dialogue with some schools in the teaching network to train educators to work with people with VI, and provides some expanded material. This action proves essential to the experience of families.

The institution itself already makes a linkage with the schools [...] teachers already know when the students are there and they are already treated in a special way (Father 5b) [...] *then she's done swimming, aquatic volleyball [...] study. The materials for studying gets here punctually* (Mother 5-B).

[...] *All they do in the institution is important. They have a class to build gifts, to do their things by themselves, dancing, swimming, and reading. They have a whole library equipped, information is also adapted. This all helped, it was a set of factors* (Mother 7-B).

The support that the institution offers is considered essential and ensures continuous care, even if the student is disassociated, or where there is the need to prioritize the care of people with increased VI, the family continues to feel welcomed by the maintenance of the link. The institution cares about the family situation and is mobilized with the intention of offering resources and accessing facilities you have available, in order to assist the family.

The support I have is just from the institution, to the emotional issue (crying), it is like a strong base! When they said that the frequency of them (IC) in the institution would decrease I collapsed, but they said they will not lose the connection. (Mother 2-B).

The family often cannot ensure resources for treatment from its own budget. Thus, this highlights the importance of the support provided by the institutions in instrumental questions in daily life, such as transport to the institution and regular school and appointment scheduling, in addition to supporting with treatment resources, such as glasses.

They (institution) take and pick up [...] he had his pair of glasses changed ten times, I guess, and every time the institution provided them (Mother 6-B).

He (IC) has already returned to the ophthalmologist at the hospital, they scheduled it (Sister 3-B). They scheduled the session and said 'you cannot miss it, because if you yourself had to schedule this session, it would take one year or two' [...] (Mother 3-B).

Support is essential in order to equip the families; from the guidelines received by professionals, the family is empowered and establishes mutual trust in the performance of care for a family member with VI.

I learned how to teach her with the institution, I do not know how to react to her (Mother 5-B). If there wasn't the institution, we would be lost (Father 5-B). We would be a fish out of water (Mother 5-B). We received support and instructions (Father 5-B).

City A

Unlike city B, which has a specialized institution with a continuous work oriented on the integrality of people with VI and their family, in city A, this support is punctual. Despite the existence of some governmental and philanthropic institutions, those support only some children and adolescents, without continuity of stimulation and learning that a child with VI demands. The closure of educational and development activities was justified by the lack of public transport or even the family's difficulty in managing the time that demanded activity, therefore abandonment occurred.

The teacher at the support institution helped him a lot. He began to learn at school, keep up with the class. And then he stopped, [...] it is very bad, no one cares for him at school, he has no support. [...] The public transport stopped going because no one wants to come pick him up here in the rural village [...] (Mother 5-A).

Discussion

The care demanded by the family experience related to visual impairment reflected unexpected changes to the routine; facing new responsibilities, constant changing and diverse readjustments, affecting financial, occupational, personal, and social levels and quality of life^{19,20}. The changes are determined by the needs arising from VI, which mobilizes the family life towards social interactions which were not present, to some extent.

In this study, the family is highlighted as a strong ally to face VI emotionally and instru-

mentally. Another study confirms our findings by showing that the support most often cited by people with physical disabilities were the relationships of the nuclear family, reported as essential for access to health care services, because they schedule consultations and accompany family member⁸.

The family that experiences a chronic condition in children and adolescents faces changes in routine, adverse situations and seeks support to sustain itself²¹. Sometimes, in situations of instability, the tools which families have to exercise care will be exhausting, especially in extended situations. Thus, as the main care provider, the family is strongly required and it is not uncommon because more than one entity is involved in this activity¹⁵. Among the family members who perform care, mothers were the most requested, followed by other members of their own household, such as older siblings, grandparents, husbands, uncles/aunts, and mother-in-laws²¹.

The movement performed by family given the weaknesses in the support network is explained by symbolic interaction through the concept of mind¹⁰. The family recognizes the inefficiency and frailty of network services and mobilizes; first, a mental activity in the search for solutions to that demand is not covered. Mental administration makes the family search for strategies to fight the problem; in the case of the study participants, seeking the family and the resources provided by them was one of the strategies used to solve or alleviate the need.

Considering the friendly interactions, a study by Vanthauze & Vieira²² assessed the perception of quality of life of adolescent students with physical, visual and hearing disabilities. For this, they used an instrument that analyzed the physical, psychological dimensions, social relationships, and environment, checking how it interferes with quality of life. For adolescents with VI, the social and psychological dimensions had the highest score. Thus, our findings that friendly relationships and positive social interactions directly stimulate dealing with disability and improving the quality of life, have been referenced.

Friendships permeated by reciprocity are a protective factor when there is a confrontation with difficulties, and in cases where there is a familiar disruption. These relationships serve as a buffer for bad feelings that may prevail with the chronic condition and the lack of family support²³.

Visually impaired people were emphatic in the statements relating to cultural activities as

support strategies. They reported performing musical activities, theater, as well as the use of virtual social networking and games on computers as a distraction, as well as environments in which differences are not seen. Research performed in order to relate the use of the internet with social support for people with VI found that social networks used, such as an online communication strategy, highlighted the positive association with social support and well-being. The authors also highlighted the potential of the internet to improve independence and social interaction for people with VI²⁴.

The theme of religiosity and spirituality has been highlighted in several studies related to chronic disease, demonstrating that these elements interfere with resilience; when there is greater access to religiousness and spirituality there is also a higher level of sensitivity to overcoming the difficulties^{21,24-27}. Among the social groups that people with disabilities participated, religious groups were the most cited⁸.

As noted in this study, health services in both cities develop care with a biomedical approach, without looking at the integrality of children and adolescents with VI and their family. Disarticulation, lack of reference, and ineffective embracement and delay in scheduling were observed more intensely in city A. Researchers observed that families of children with chronic disease experienced a lack of communication between professional and family, a long wait for diagnosis, lack or weakness in providing emotional support and information^{27,28}, and inexistence of reference and counter reference actions. In addition, the families do not feel embraced, which interferes negatively in the perception of social support received²⁸.

Frustration with the lack of resolution was also discussed in the families' statements. Uncertainties regarding therapy and prognosis, in addition to conflicting information, make the family search for other health services²⁸.

In the experience of the families and their members with VI living in city B, finding a specific support service was remarkable and essential, because it acts directly towards the benefit of the child's development, provides support for the family as a care unit, and also because of the dialogue performed with the regular school where children with VI were enrolled. Studies corroborate our findings and bring the importance of health services for the development of people with visual impairment, particularly elucidating the dependence of rehabilitation, clinical care,

and emancipation when faced with a chronic condition²⁹.

The sessions of the specialized institution supply gaps when the family cannot provide care alone, because it often lacks the expertise to do so. There are qualified professionals and appropriate technology in the specialized institution. Thus, all these factors associated repercussions in heterogeneous experiences among social actors of the different cities in the social and educational inclusion.

In this experience, the families of city B mention the benefits of having a support network, such as the institution focused on the peculiarities of the members with VI. An investigation performed with blind people determined that the participation in activities in a specialized institution was an essential experience for these individuals to be able to live and recognize others who experienced similar situations, being characterized as a process of rebuilding³⁰.

The authors also explore the need for family involvement in the rehabilitation and the benefits provided in this process, such as changes in autonomy, allowing for considerable modifications in daily life, on issues related to social participation and performance of individual activities³⁰.

The support provided by this specialized institution may also be explained by the concept of SI "assume the role of other", which puts one human being in the position of taking another's perspective, one can see the world from the perspective of the other, which is essential for establishing communication and interaction¹⁰. The direction of this institution is occupied by a person with VI, and it might make the difference in how the institution's activities are performed, due to an individual's perception of the activities and the sensitivity to recognize the needs of people served and their families.

Despite considering the work developed by the support institution for people with VI of city B primordial, it is known that structures like this are not developed with government resources in all cities, due to the small number of people with the diagnosis or even the non-involvement of society in relation to the creation of philanthropic institutions. Thus, there is the need for a better quality dialogue between the health services and the family, and also between the management of education and school, which qualify the relations between them and provide information and appropriate support facing the individualized care and the need for each family and person with VI, so that their demands are contemplated.

It is up to health professionals to perform an action to expand and facilitate the participation of people with disabilities in social groups, and provide support to families in relationships focused on care and assistance in health⁸. Social networking is built in the continuity of the whole trajectory experienced by children and adolescents with VI and their families, so each meeting should be marked with solidarity and cooperation to maintain the connection between professional and family²⁸.

Final considerations

Considering the concept of a support network, it was deduced that the social support is offered for children and adolescents with visual impairment and their families. However, it cannot be described as a network, especially regarding the experience of families of city A. There is no coordination between the services to function effectively as support networks. It is noticeable that the “junctions” in support and interface between organizations is eventually made by the family, friends, and through spirituality and religiosity, in order to ensure at least minimal protection.

The health services demonstrate failure in the care of children and adolescents with VI and their families. The reality of the families living in city B was different because the specialized institution establishes a relationship with the family support to meet the needs of people with VI and sometimes in a more expanded scope, the family. In the

same city, it was possible to capture failures due to the lack of referral performed by health services.

With this study, it was found that family nursing has meant little to the person with VI and even less to the family as a whole. The family is pleased when they see the child and/or adolescent is supported to develop as close to normal as possible. Despite the challenges faced in acquiring support, the family can rearrange itself, care for its members, and minimize such suffering.

In their statements, families attributed different meanings to their experiences, which allowed for accessing the cultural process and the experience of each, and how to understand the social support network, its importance, and influence, meeting the premises of Symbolic Interaction.

This study contributes to the work of these professionals so that they try to listen and care for the family, guide them properly so that they are empowered, as the network of accessible support and care strategies for people with VI, and that it is established in partnership with those involved. It also allows for thinking about ways to improve and make the network of social support functional, which will have repercussions in the resilience process of a chronic condition, and in health promotion.

Despite the study limitations in terms of focusing only on the families' report and not listening to other members of a support network, it contributes significantly in the unveiling of the support network, under the familiar prospect of their absence or frailty in a relationship with the families studied.

Collaborations

MC Barbieri and GVDZ Broekman worked in the conception, design, data collection and interpretation, writing, review, and approval of the version to be published; ROD Souza, RAG Lima, and M Wernet worked in review and approval of the version to be published; G Dupas worked in the conception, design, data collection and interpretation, writing, review, and approval of the version to be published.

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