

Interaction with children with cerebral palsy: communication and stigma

Interação com a criança com paralisia cerebral: comunicação e estigma
La interacción con los niños con parálisis cerebral: comunicación y estigma

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ABSTRACT

Objective: This study aimed at understanding the way in which communication between families and children with cerebral palsy is established. **Methods:** This is a study with qualitative approach, conducted in a municipality in the countryside of the State of São Paulo, with six families of children with cerebral palsy living in the area of social vulnerability. Data collection took place in the first half of 2011 by means of semi-structured interviews. The symbolic interactionism was used as a theoretical-methodological benchmark. The thematic content analysis, according to Bardin, was applied as an analytical method. **Results:** The data analysis gave rise to the theme "Family Interaction", composed by its respective categories. The results show that families and children can develop strategies, from interaction, that go beyond the meaning of words, thus building an effective communication. **Conclusion:** The health care professionals can contribute through interventions, thus becoming instruments for enhancing the communicational process. Nevertheless, such skill was not considered; moreover, moreover, informational support was not realized as effective.

Keywords: Nursing; Communication; Cerebral Palsy; Child; Family.

RESUMO

Este estudo teve como objetivo compreender como a comunicação entre família e criança com paralisia cerebral se estabelece. **Métodos:** Trata-se de um estudo de abordagem qualitativa realizado em uma cidade do interior de São Paulo, com seis famílias de criança com paralisia cerebral residentes em área de vulnerabilidade social. A coleta de dados ocorreu no primeiro semestre de 2011 por meio da entrevista semiestruturada. Utilizou-se o interacionismo simbólico como referencial teórico-metodológico e a análise de conteúdo temática, segundo Bardin, como método de análise. **Resultados:** Da análise dos dados emergiu o tema "Interação Familiar", composto por suas categorias. Os resultados revelam que família e criança desenvolvem estratégias, a partir da interação, que ultrapassam o sentido das palavras, construindo uma comunicação efetiva. **Conclusão:** Os profissionais de saúde podem contribuir por meio de intervenções, tornando-se potencializadores da comunicação. Tal potencial, entretanto, não foi considerado, além de o apoio informacional não ser efetivo.

Palavras-chave: Enfermagem; Comunicação; Paralisia cerebral; Criança; Família.

RESUMEN

Objetivo: Este estudio objetivó entender cómo la comunicación entre la familia y el niño con parálisis cerebral se establece. **Métodos:** Estudio cualitativo realizado en la ciudad de São Paulo, con seis familias de niños con parálisis cerebral que viven en la zona de vulnerabilidad social. La recolección de datos ocurrió en el primer semestre de 2011 mediante una entrevista semiestructurada. Se utilizó el interaccionismo simbólico como un análisis de contenido teórico-metodológico y temático, según Bardin, como método de análisis. **Resultados:** Del análisis de los datos surgió el tema "Interacción Familiar", compuesta por sus categorías. Los resultados revelan que la familia y el niño desarrollan estrategias de interacción, más allá del significado de las palabras, construyendo una comunicación efectiva. **Conclusión:** Profesionales de la salud pueden ayudar a través de intervenciones, convirtiéndose en la comunicación aumentativa. Este potencial, sin embargo, no fue considerado y el apoyo informacional no se comprobó efectivo.

Palabras-clave: Enfermería; Comunicación; Parálisis Cerebral; Niño; Familia.

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INTRODUCTION

Cerebral palsy is characterized by a set of cerebral disorders, with stationary character, arising from in utero or during the beginning of the life, which affects physical functioning, self-care activities, social interaction, and communication. Cerebral injuries can limit, to different extents, the ability of oral, symbolic or linguistic production, or even of children with cerebral palsy have at least some oral/motor changes that impairs speech. Physical changes of the jaw structure, lips and tongue, imply difficulties for articulating words².

Due to the fact that communication is a mode of interpersonal interaction, in which speech, language mechanisms in social interaction³, the oral/motor changes influence the communication of children with emotion and feelings of those involved⁴.

In order to express its concerns, the human being has two dimensions or modes of communication: the verbal communication (psycholinguistics), which requires the use of words and of the speech for transmission of messages, and the non-verbal communication (psychobiological), which consists of gestures and body and facial expressions. The latter plays a leading role in the situation under study, by representing 60% of the way of transmitting messages of individuals with cerebral palsy⁵. Such children communicate according to their cognitive, sensory and motor abilities. They can direct the gaze or a body part that has better control and issue sounds, thus establishing differentiated forms of communication². From the conviviality with the affected child, the family learns and understands the communicational process and, as the interaction between child/family strengthens, communication becomes more effective.

Despite the complexity of this experience, the family core does not keep silent, conversely, believes and enhances the development of this interaction, by offering conditions for the child to interact not only with family members, but also with other segments of society, even with occurrences of an erroneous and biased perspective of the disease in several occasions⁴. Situations involving communication problems extrapolate the child/family relationship and the home environment, by passing through questions relating to the care, as well as the relationship of the family core/child with health care professionals. These professionals have the capacity to meet the need for information and access to services, but the literature indicates that this relationship is ineffective, besides being emotionally poor. Accordingly, the family finds it difficult to obtain information and identify resources available in the community, as well as to envisage future prospects for the child⁶.

Before the challenges related to the theme of communication in families of children with cerebral palsy and the gaps existing in the literature that deal with this topic, it was asked how important the communication in this experience is, because it is through it that the family core can relate to the child. In light of the foregoing, this study aimed at understanding the meaning of how communication between families and children with cerebral palsy is established. For this purpose, it is presented the importance of understanding

how the communicational process is developed, as well as the difficulties encountered by the family before the situation, whether in relation to the child or to the health care services.

METHOD

This study was conducted through qualitative method. In qualitative researches, the selected method for performing the data analysis must enable the comprehension of the meanings assigned to experiences of research subjects and the overview of the results. It encompasses a set of techniques that gives visibility to experiences, thus turning them into representations. In nursing, qualitative methods allow unravel the emerging problems of the everyday of the practice⁷.

The symbolic interactionism was used as a theoretical-methodological benchmark and the thematic content analysis proposed by Bardin was applied as an analytical method. The symbolic interactionism is a benchmark that is based on human relationships, so that it evaluates the meaning that individuals assign to their experiences. It understands the behavior as a set of interpretive processes and factors in which the human beings conduct their actions through the meaning assigned in the social interaction. This interactionist perspective allows us to understand the human being in its relationships with society, with itself and with each other. Furthermore, the symbolic interaction and communication established by the individual allows the uptake of meanings, feelings, emotions, behaviors and expectations in the face of the experienced situation. Thus, through the symbolic interactionism, the human being is understood as an individual who experiences continuous interactions, by being active and with freedom of choice⁸.

The thematic content analysis of Bardin is a set of techniques used to analyze the communicational process, and this technique is developed in three stages: pre-analysis (fluctuating reading and hypotheses formulation); material exploration (coding and classification in categories) and treatment of obtained results and interpretation (reflection process)⁹.

The research participants were families of children with cerebral palsy who resided, at the time of data collection, in regions with vulnerability 5, in a municipality in the countryside of the state of São Paulo. After delimiting the neighborhoods of the urban area with vulnerability index 5, it was found a list with addresses of 20 families for contact. The study subjects were 12 participants from six families of children with cerebral palsy (Table 1), with the following inclusion criteria: having a child with cerebral palsy and being resident in the area with São Paulo's Social Vulnerability Index (known as IPVS) with level 5.

The IPVS is an instrument that maps the areas according to their degree of vulnerability, which are composed of a combination of demographic and socioeconomic factors. It is used to know the demands of the population of the enrolled area, in order to develop public policies to fight against the social vulnerability. The level five is the maximum index of social

Table 1. Identification of families of children with cerebral palsy participating in this study

Family Identification	Child Identification	Interviewed Members (relationship with child/age/occupation)
Family 1	Child 1 Male Gender Nine years	Mother, 42 years, housewife Sister, 17 years, student Sister, 13 years, student Brother, 15 years, student Brother, 12 years, student
Family 2	Child 2 Male Gender Twelve years	Mother, 43 years, housewife
Family 3	Child 3 Male Gender Nine years	Mother, 41 years, housewife Father, 40 year, factory worker (machine operator)
Family 4	Child 4 Male Gender Nine years	Mother, 41 years, seamstress
Family 5	Child 5 Male Gender Ten years	Mother, 47 years, housewife
Family 6	Child 6 Female Gender Ten years	Mother, 48 years, housewife Sister, 10 years, student

vulnerability and is assigned to the regions that have the worst socioeconomic conditions¹⁰.

Semi-structured interviews were performed in the families' homes. This way of conducting the interview allows direct collection of information, adjustments in the trajectory of the interview and clarification of dubious questions¹¹. Through guiding questions, families were invited to share their experiences. The interviews were conducted in the families' residences, with a previous agreed time and in the presence of all family members who were within the residence at the time of the interviews. The speeches were completely recorded and transcribed, and its closure was held by theoretical saturation, which is a tool used by researchers to establish or close the size of their samples when obtained data begin to present some redundancy⁷. The collection took place in the first half of 2011. In order to elucidate the results, the participants' speeches were presented by means of the following standardization: for each cutout of speech, the sender, its relationship with the child, the number of the interview and the page in which the stretch was situated were identified.

All precepts of the Resolution nº 196/96, which regulates the development of researches involving human beings, were followed. This survey was approved by the Research Ethics Committee from the Federal University of São Carlos, through the Opinion number 094/2011 and CAAE nº 5525.0.000.135-10 (Annex I).

RESULTS AND DISCUSSION

This paper is part of a larger study¹², in which the process of collecting and analyzing data has allowed to identify four

major themes representative of the family's experience in the conviviality with the child affected by cerebral palsy. Here, it should be highlighted the theme related to "family interaction", which allows the identification of the existing communication in this scheme of relationships.

The communication matters experienced by the family unit are related to the child itself, to other people, to health care professionals and communicational process with other families. Thus, four strands of communication were considered in this context: the family in its relationship with the child creates a bond of love and comprehension that enables communication between them; as for the other people to whom it interacts, suffers from a lack of understanding and sensitivity, and the interaction is permeated by prejudice; the health care professional that, during communication with family, showing shows difficulty in relationships and almost never considers the child with a skill to establish communication; and the interaction with other families experiencing the same disease, with which an effective communicational process is established, realized as very important for the experience of them all. These spheres are presented by their respective themes: "Understanding through the gaze"; "Not believing in communication capability"; "Ineffective communication with the health care professional" and "Sharing information".

Understanding through the gaze

The affective bond that the family establishes with the child is so strong that communicational strategies are developed in order to meet the child's manifestations. The conviviality enables the

family to know and understand its reactions and expressions, in addition to comprehending the way of gazing and realizing what the child is feeling. This means that communication goes beyond the meaning of words. In this sense, the family understands the meaning of feelings and desires through gestural expressions. Affection, love and conviviality strengthen the bonds and allow parents to recognize the children's manifestations. They develop their own ways of communicating, which makes interaction a rewarding action. The child cannot express itself in verbal forms, but, in addition to demonstrate its desires, also demonstrates its understanding of what is being communicated. This interaction is perceived as satisfactory by those involved.

Through interaction established with the child, the family understands the communicational process. Children demonstrate to be aware of what is being said and correspond by means of gestures. The family, by valuing communication and believing in the child's understanding, enhances the development of communication while maintaining a constant interaction/dialogue with the child.

"He understands his own way, and we also understand our way!" (Mother, 11, P.2).

"...he communicates with us, in his own way." (Mother, 13, P.4).

"I talk a lot with him here at home. I'm in the kitchen and he is in the room and mutters. I say: 'Mom's here, what do you want?' I sing a song, I play a lot! He communicates through sounds like 'ahhn ... huum', gaze, sometimes laughs. Sometimes, when grumbling 'mother' you should stay here. But the most is through sounds like 'hum hum' and by stretching the head! Sometimes, we're here watching TV at night and he starts to whisper 'hum' (he stretches his neck towards the bedroom) and look for the bedroom! Then, I already know that he wants to go to bed! Or out of home! When we say 'let's go out for a walk,' he laughs, gets agitated, laughs and shakes himself! Do you understand? All happy! So we know!" (Mother, 15, P.7).

The effectiveness of the established communication is developed by means of a set of factors that are not restricted to speech¹. The conviviality and the interaction established enable awareness in understanding the other being. This work has made clear that conviviality and willingness allow the family to understand the child's nuances, thus establishing communication through attitudes that go beyond words. When realizing the need for communication, they learn to develop it¹³. Such observation is highlighted in a study that considers the gestural behaviors such as smile, direction of gaze, indications and vocalizations as fundamental roles of communication of these children¹⁴.

Not believing in communication capability

Every stigma is related to the inferiorization of a social member or in any condition, thus leading it into disrepute.

The social mark results in unfavorable judgments of people who experience this phenomenon, by differentiating them and hence inferiorizing them in relation to the group¹⁵. In the condition of cerebral palsy, the stigma occasionally makes it complicated to hold the relationship between family and society. Not understanding the context and the consequences of such a relationship generates an early concept that does not consider the ability to interact or even the comprehension of these children. The lack of sensitivity is undeniable and impacts the family unit. Even family members who have daily contact and are aware of the clinical picture of the child occasionally have difficulty in communicating and interacting with it. Such people do not seem to comprehend the importance of communication, thus devaluing the efforts of those who seek such a bond. Thus, family members who do not realize the meaning of this interaction are not truly involved with the child, by creating a barrier, limiting their relationship to the physical care, without interact and verbally stimulate the child.

"Sometimes the (child) says 'oooo'. He does not speak, but communicates like this. My husband does not say anything and then I say 'talk with the boy in order to make him realize that you understand him!' I talk to him (child)! But, my husband looks and says I'm crazier than he thought!" (Mother, 14, P.7).

"... We talk with him and some people do not understand, so they say 'why are you talking to a child who does not understand?' But, we understand, through the gaze, through him 'manifest'. Then, we can understand." (Father, 13, P.4).

Communication difficulties resulting from cerebral palsy can interfere in the socialization processes of the child, since the primary means of social interaction takes place through speech². This study has shown that several family members establish effective interaction with the child and produce meaningful communication. Nevertheless, the family does not realize availability on the part of society and of health care professionals to interact with it, thus creating a relational experience permeated by misunderstanding and prejudice against the child with cerebral palsy. The stigma existing in this condition leads people with differentiated cognitive conditions to be considered vulnerable and unable to acquire autonomy. Accordingly, the communicational skill is underestimated in the face of the imposed difficulties⁶. Such fact is explained through the usual loneliness and isolation experienced by people with disabilities, factors derived from restricted social relationships or ineffective support networks, when communication, in this process, is an important way to reduce such a feeling¹⁰.

The prejudice and social exclusion of people with disabilities is an old fact, but still present in society. These individuals are continually targets for biased attitudes and insensitive actions, with no respect to their rights as citizens. Usually, one focuses attention on the difficulties, limitations and appearances rather

than on their skills and capabilities¹⁵. The skills are minimized before the concept of disablement and disability, thus reducing their chances of achievement in several spheres¹⁶. The family fights daily against prejudice and stigmatization, by mobilizing itself in seeking rights and accessibility.

Ineffective communication with the health care professional

The therapeutic demands of cerebral palsy lead the family to constantly be with health care professionals. Such approach has the potential to extrapolate the scope of physical care and can widely be therapeutic. Nonetheless, not always it establishes a partnership in care and the lack sensitivity in relation to the family is usually realized. Not even the communication is effective in the informational scope, which is an explicit fact in the family difficulty in finding professionals to clarify the diagnosis and clearly inform about what to in relation to the child. The family, without explicit information about the child's diagnosis, only realizes that something is wrong when it does not have a satisfactory development for age, and/or starts to attend specialized health care services. This gap in communication with the health care professional makes the family walking even harder in the search for resources that enhance the life quality of the child.

"We stood out of mind! We only noticed the actual situation over the course of time: because he did not crawl around and did not keep on standing! Then we realized he was a different child and take him to the sessions of respiratory therapy!" (Mother, I1, P.6).

"Nobody told me! They were prematurely born and left the hospital and I suddenly noticed that something was wrong. The doctor advised me to take them to perform physical therapy; there, practitioners told me that the babies needed of nine months of physical therapy and these nine months had gone! Then I went to ask the physiotherapist, at the time: 'weren't there only 9 months? But nine months have already gone', then she said 'No! It might be 1 year, 2, 10, 30 years!' And even today we're still performing physiotherapy! So we adapt ourselves as the new things appear to us!" (Mother, I2, P.2).

"I think after about five months, when he was at home, he turned his little eyes and we thought that's funny, but we didn't know what it meant! Then I took him to the pediatrician's room and she said, 'Mom, this is not funny! This is a seizure!' That happened, when he already was one and a half years old, roughly!" (Mother, I4, P.3).

Because of the fact that such care experience is most often solitary and focused on a person (mother figure is invariably the center of attention), the stress level of parents of children with cerebral palsy is higher than normal in the population. Thus, this experience can also be permeated by feelings of weakness, by

constant concern and, sometimes, by guilt, besides the overload generated by the continuous need for care shares^{1,4,6,17}.

Health care professionals have the skill to minimize the negative aspects of the chronic condition through the partnership of care. To that end, the health care service must be coordinated in order to provide comprehensive health care and to maximize the family power¹⁶. In this care, it is also important to recognize family's needs, by seeking to strengthen and enhance the coping mechanisms and providing resources and autonomy to the family unit^{4,6}.

Although the partnership of care has proved to be more effective, the feelings that emerged from the interviewees' reports indicate that the family feels excluded from the process of decision-making about the act of caring. This finding is consistent with the literature, when it identifies gaps in the topic of communication¹⁵. This picture can be observed due to the biomedical culture that "verticalizes" the process of information and hinders the establishment of an effective communication, sometimes because of the differences between the professional language and the patients' language, and also by the stigma that mediates the meeting.

Specifically in the nursing field, the study highlights that the family does not recognize the role of the nursing professional as a resource of informational support¹⁶, which was also observed in this survey. A sensitive gaze of professionals in relation to this experience, besides making the conventional signs of communication flexible is essential to establish an effective channel of interaction². Through communication with the family, the health care professionals value the importance of child care, because they will transmit necessary information about the disease, thus including the family in the process of therapeutic decision, so that it involves itself in the rehabilitation of the individual and feels sureness in conducting care shares¹⁸.

Sharing information

The therapeutic necessity required by children with cerebral palsy lead their families to attend health care services that have customers with the same pathology and experience the same situation. Such fact makes individuals to get closer to each other and exchange experiences on children's behavior, in addition to their clinical and therapeutic conditions.

In light of the foregoing, communication is produced by means of conviviality and relationship with other families. This process is often initiated in order to answer questions, when families facing the situation for a longer time decide to share trajectories that enhance the action of the "beginner" family and provides greater welfare to the child. This conviviality with other family experiences provides learning about the care of children with cerebral palsy, besides allowing an exchange that soothes and comforts.

"It was there that I learned (conviviality with other mothers). You know, you can learn the right way to care of the child, because the mothers tell you. The daily routine itself

can make you more able to learn how to deal with the situation! Nowadays, I have my own skills to deal with the situation. That was difficult in the beginning because I was lay! I'm not an expert now, but I've learned!" (Mother, I2, P.1).

"Sometimes I was in the queue of the small health unit or even in the ICU and I saw somebody and started talking to him/her. Sometimes the person had a child, or a relative in the same situation, then I began to talk and figure things out. We can still discover a lot of things through information from mothers to mothers undergoing this same experience!" (Mother, I4, P.2).

"So, it is because one mother tells to another one, those who have more experience! Those who have the eldest children in relation to the (child), who already go out for a ride with them, are the ones that tell us the procedures!" (Mother, I5, P.5).

The search for information about cerebral palsy is a struggle experienced by families in the attempt to learn the best way to act with the child and provide suitable care to it. Therefore, this pathways travelled by the families produce communication with other mothers, through the need to exchange experiences about the disease at stake, with people that offer support, attention and listening^{17,18}.

As pointed out in the literature, the families of children with cerebral palsy suffer from a lack of information about the disease, as well as through the exclusion by health care professionals. These families find support by means of mutual living by forming a network where they exchange experiences about the strengths and difficulties faced in their daily lives, thus establishing an effective communicational process^{16,17}.

This conviviality among families experiencing the same situation conveys knowledge to the family core, by enabling its members to perform actions that they consider unable to perform, in addition to minimizing obstacles faced in their daily lives together with the affected children¹⁷.

CONCLUSION

The clinical picture, usually exposed through cerebral palsy, involves a set of consequences that makes it difficult to hold communication with the child in the traditional manner. Nonetheless, this does not mean that it has no skills for developing communication. In this study, it was found that families and their children can develop strategies, from interaction, that go beyond the meaning of words, thus building an effective communication.

The health care professionals can contribute through interventions, thus becoming instruments for enhancing communication and developing strategies to promote family autonomy and communication with children. Nevertheless, in this

study, the aforementioned skill was not considered; moreover, informational support was not realized as effective. It becomes clear that the information achieved by the family unit come through interaction with individuals who experience a similar situation, with which they establish an effective communication, which addresses the difficulties of care of children with cerebral palsy and strategies for overcoming troubles.

The data indicate the need to reflect on the aspects of the communicational process and rethink the care shares in a comprehensive manner. Careful listening and informational support, mentioned as essential factors to the therapeutic process need to be rescued.

The limitations identified in this study are related to lack of comprehensiveness of the family's perception on longitudinal changes in the child development and alterations in the form of communication. Nor does it deeply investigate communication strategies developed by the family in relation to the affected child. Furthermore, the lack of publications on this specific theme hampers comparison of the results of this study with the conclusions of the general literature.

Based on these outcomes, this paper identifies the conduction of detailed studies about communication as something mandatory, by considering the need to sensitize health care professionals to become a source of support for families experiencing cerebral palsy, as well as other situations of chronic condition.

REFERENCES

1. Svedberg LE, Englund E, Malker H, Stener-Victorin E. Comparison of impact on mood, health, and daily living experiences of primary caregivers of walking and non-walking children with cerebral palsy and provided community services support. *European Journal of Paediatric Neurology*. 2010;14(3):239-46.
2. Geytenbeek J. Prevalence of speech and communication disorders in children with CP. *Dev Med Child Neurol*. 2011 jan;53(1):10-1.
3. Araújo MMT, Silva MJP. O conhecimento de estratégias de comunicação no atendimento à dimensão emocional em cuidados paliativos. *Texto & contexto enferm*. 2012 jan/mar;21(1):121-9.
4. Pereira LMF et al. Acessibilidade e crianças com paralisia cerebral: a visão do cuidador primário. *Fisioter. mov*. 2011;24(2):299-306.
5. Singurdardottir S, Vik T. Speech, expressive language and verbal cognition of preschool children with cerebral palsy in Iceland. *Dev Med Child Neurol*. 2011 jan;53(1):74-80.
6. Nunes MDR, Dupas G, Nascimento LC. Atravessando períodos nebulosos: a experiência da família da criança portadora de Síndrome de Down. *Rev. bras. enferm*. 2011;64(2):227-33.
7. H. Symbolic interactionism: perspective and method. Berkeley: Berkeley(CA): University of California Press; 1969.
8. Bardin L. Análise de conteúdo. Lisboa(POR): Edições 70; 2008.
9. São Paulo (Estado). Fundação Sistema Estadual de Análise de Dados. Índice Paulista de Vulnerabilidade Social [citado 2011 jan 29]. Disponível em: <<http://www.seade.gov.br/projetos/ipvs/apresentacao.php>>.
10. Dark L, Balandin S, Clemson L. Communicating about loss: Experiences of older Australian adults with cerebral palsy and complex communication needs. *Communication disorders Quarterly*. 2011 may;32(3):176-89.

11. Fontanella BJB, Ricas J, Turato ER. Amostragem por saturação em pesquisas qualitativas em saúde: contribuições teóricas. *Cad. Saude Publica*. 2008 jan;24(1):17-27.
12. Baltor MRR. Doença crônica na infância no contexto de vulnerabilidade social: a experiência da família [dissertação]. São Carlos(SP): Universidade Federal de São Carlos; 2011.
13. Wadnerkar MB et al. A single case study of a family-centred intervention with a young girl with cerebral palsy who is a multimodal communicator. *Child Care Health Dev*. 2012 jan;38(1):87-97.
14. Godin KM, Carvalho ZMF. Sentimentos das mães de crianças com paralisia cerebral à luz da teoria de Mishel. *Esc. Anna Nery*. 2012 jan/mar;16(1):11-6.
15. Palisano RJ, Almarsi N, Chiarello LA. Family needs of parents of children and youth with cerebral palsy. *Child Care Health Dev*. 2010 jan;36(1):85-92.
16. Pedro ICS, Rocha SMM, Nascimento LC. Apoio e rede social em enfermagem familiar revendo conceitos. *Rev. latino-am. enfermagem*. 2008;16(2):324-7.
17. Andrade MB, Vieira S, Dupas G. Paralisia cerebral: estudo sobre o enfrentamento familiar. *Reme, Rev. Min. Enferm*. 2011 jan/mar;15(1):86-96.
18. Sandor ERS. Conhecendo a família da criança com doença crônica: repercussões no contexto familiar [dissertação]. São Carlos(SP): Universidade Federal de São Carlos; 2009.