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NURSING PROFESSIONALS' FEELINGS ABOUT FAMILY ABANDONMENT OF PATIENTS WITH CEREBRAL PALSY

SENTIMENTOS DOS PROFISSIONAIS DE ENFERMAGEM FRENTE AO ABANDONO FAMILIAR DE PACIENTES COM PARALISIA CEREBRAL

SENTIMIENTOS DE PROFESIONAL DE ENFERMERÍA FRENTE AL ABANDONO DE LA FAMILIA DE PACIENTES CON PARÁLISIS CEREBRAL

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ABSTRACT

Objective: to know the feelings of the nursing professionals about family abandonment of cerebral palsy patients in long-stay institutions. **Method:** descriptive and exploratory study, with a qualitative approach, at a philanthropic neurological hospital in São Paulo / SP. Eleven nursing workers participated, during the months of november and december, 2012, through semi-structured interview. For data analysis, was used the content analysis technique. **Results:** emerged the following categories: *Category 1:* The sadness for the family abandonment; *Category 2:* Trying to understand the reason for the abandonment; *Category 3:* Trying to compensate the family abandonment; *Category 4:* The importance of family. **Conclusion:** for professionals, family participation in the care and follow-up of these patients would be extremely important for their development. **Descriptors:** Cerebral Palsy; Institutionalization; Nursing.

RESUMO

Objetivo: conhecer os sentimentos dos profissionais de enfermagem frente ao abandono familiar de pacientes com paralisia cerebral em instituição de longa permanência. **Método:** estudo exploratório-descritivo, com abordagem qualitativa, em um hospital neurológico filantrópico, no interior de São Paulo/SP. Participaram 11 trabalhadores da enfermagem, durante os meses de novembro e dezembro de 2012, por meio de entrevista semiestruturada. Para análise dos dados utilizou-se a Técnica de Análise de Conteúdo. **Resultados:** emergiram as seguintes categorias: *Categoria 1:* A tristeza diante do abandono familiar; *Categoria 2:* Tentando compreender o motivo do abandono; *Categoria 3:* Tentando compensar o abandono da família; *Categoria 4:* A importância da família. **Conclusão:** para os profissionais a participação familiar no cuidado e acompanhamento destes pacientes seria de extrema importância para seu desenvolvimento. **Descritores:** Paralisia Cerebral; Institucionalização; Enfermagem.

RESUMEN

Objetivo: conocer los sentimientos de los profesionales de enfermería al abandono de la familia de pacientes con parálisis cerebral en instituciones de larga estadía. **Método:** estudio exploratorio y descriptivo, con un enfoque cualitativo, en un hospital neurológico filantrópico en Sao Paulo / SP. Los participantes del estudio fueron once trabajadores de enfermería, durante los meses de noviembre y diciembre de 2012, a través de entrevista semiestructurada. Para el análisis de datos, se utilizó la técnica de análisis de contenido. **Resultados:** surgieron las siguientes categorías: *Categoría 1:* La tristeza por el abandono de la familia; *Categoría 2:* Tratar de entender el motivo del abandono; *Categoría 3:* Tratar de compensar el abandono de la familia; *Categoría 4:* La importancia de la familia. **Conclusión:** para los profesionales, la participación de la familia en la atención y el seguimiento de estos pacientes sería muy importante para su desarrollo. **Descriptores:** Parálisis Cerebral; Institucionalización; Enfermería.

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INTRODUCTION

Cerebral Palsy (CP) is a result of a static lesion that affects the central nervous system in structural and functional maturation phase. It may occur in pre-, peri- or post-natal period, being a sensorimotor dysfunction, which results in motor and intellectual limitations.¹

In milder cases, the patient may have a normal life without obstacles, but often have central motor impairment, causing major impact on speech, hearing, vision, motor skills, swallowing in several degrees of commitment, and on intellectual level.²

Disability has an individual meaning and, consequently, different impacts on each person and each family, because it leads to limitations for life that will require adaptation of everyone in the family. So, how each person fits to deal with disability is an individual conduct and influence on family dynamics, and their interaction with the patient.³

Most people with cerebral palsy become dependent on their families due to the limitations in many cases, since they do not take baths alone, do not wear or feed themselves, make use of diapers and cannot move from the wheelchair to the bed.⁴

In periods of hospitalization, the presence of a family companion is necessary and important for the evolution of the patient, once it helps in emotional support and brings security to the internee. The accompaniment of the family motivates the patient to have an interaction with the outside world, thus, ensuring a link to society.⁵

The family decides for the institutionalization of a member, trying to provide a better life, care and comfort than those the family can offer.⁶ In some situations, the family is unable to care and to reconcile the activities such as work, home, and patient care. And whenever anyone in the family is able to care for the patient, institutionalization is the solution found for this problem.

The family is considered the main caregiver, and essential for satisfactory development of the patient, whereas receiving the CP diagnosis impacts so much that the family feels unable to care for the child.⁷

For the Family, having a child with CP is so striking that difficults bonding, embracing the child, understanding the information; affects the daily routine, commits the dreams and projects of each member of the family, which

disrupts, being necessary a long process to restructure the balance.⁸ The effects of the disease affects various dimensions of family life, causing social disconnections and pain that affect all family members.⁹ And, for the difficulty caused by the disease to be alleviated, nursing becomes essential to support families in the encouragement and search for normalcy. However, for the care to be effective, an holistically performed, consistent and free from prejudice assistance is necessary, looking at the human being as a whole, as a being who has the same needs as any other human being.¹⁰

For this care to happen, health professionals should be competent and aware of this issue, in order to implement and encourage membership of a therapeutic project to reach the needs of the patient and the family.

Furthermore, the importance of the family in caring for the patient with cerebral palsy is essential. Without that family support, the patient depends on the care of health professionals. Understanding the feelings of professionals handling these patients and family abandonment becomes important to help providing a better care.

This study aims to know the feelings of the nursing professionals regarding family abandonment of cerebral palsy patients admitted to a long-stay in/stitution, questioning: What is the feeling of the nursing professionals to family abandonment of cerebral palsy patients in long-stay institution?

METHOD

Exploratory and descriptive study, with a qualitative approach. The data production was held in a philanthropic long stay neurological hospital, in the state of São Paulo/SP, maintained by pensions and retirements of patients living in the institution, and community donations. The hospital currently houses 60 patients - adults and children living in the institution. The study involved eleven nursing professionals: nurses, technicians and assistants, working in the institution for at least one year. The interviews were conducted through semistructured instrument, during the months of november and december, 2012. Data analysis adopted the Content Analysis Technique¹¹ which structured the study in the following categories: **Category 1:** The sadness for the family abandonment; **Category 2:** Trying to understand the reason for the abandonment; **Category 3:** Trying to compensate the family abandonment;

Category 4: The importance of family.

To preserve the identity of respondents, they were identified by the letter P followed by the number as the interviews took place, eg P1; P2; P3. The project was approved by the Research Ethics Committee in Opinion nº 151,901, according to Resolution nº 196/96 - recommendations of the National Health Council, repealed by 466/12.¹²

RESULTS AND DISCUSSION

Eleven staff participated in the interviews, ten technical/nursing assistants and one nurse, who worked from one to 20 years in the institution.

Through the speeches of the officials, it was possible to grasp the reality that outlines their experience and feelings concerning the family leaving the patient with cerebral palsy. From the interviews yielded the following categories: 1) The sadness for the family abandonment; 2) Trying to understand the reason for abandonment; 3) Trying to compensate the family abandonment; 4) The importance of family.

• **Category 1: The sadness for the family abandonment**

Nursing professionals who deal in their daily work with abandoned patients, show a great sadness when referring to the interneers.

It brings me deep sadness to know that many of these patients are abandoned by their own families, I do suffer to know that. I think that the simple fact of visiting would be the minimum to be done for them (P1).

Oh, we're this sad to know the lack of interest, lack of love that the family sometimes show, for example, when the child is born and it's seen that the baby already has this kind of problem, then the lack of love is in not being careful, in abandoning (P3).

[...]knowing that there is "children" here who have successful family, and the family has chosen to intern them here. It also saddens me knowing that you have many here who has no family and came here because they no longer have father or mother, and other family members have chosen to send you here. I'm sad (P11).

Sadness is a present feeling when there is emotional involvement and, before the relation between nursing worker and patient with cerebral palsy, there is no denying that a great emotional involvement permeates this relationship, leading professional to suffer before the situation of these patients.¹³

Health care workers directly coexists with pain, loss and death, and this leads to the experience of their internal processes, such as

fragility, vulnerability, fear and uncertainties.¹⁴ Regarding specifically the nursing staff, there is a great risk of emotional collapse due to daily care of patients, leading to a more intense contact with pain and suffering.¹⁴ This is intensified when the nurse deals also with the emotional care and feel responsible for the patients, since they are abandoned by their families.

♦ **Category 2: Trying to understand the reason for abandonment**

The reports show the need for professionals to find a reason for the family abandonment. Many of them did not know the relatives of the patients, but still try to understand the reason for the abandonment.

Sometimes family members leave for failing on hanving conditions of care, supportive environment, access to expensive medications, available time to be with them, but can also be for the convenience for not feeling forced to carry this "burden" that life has given them(P2).

I believe most of them is on lack of conditions, although some of them do not care because they do not want or there is no love(P9).

Financial, cultural information about the syndrome that the patient has and, most importantly, love, because one day they can be in that situation (P10).

It is difficult to have such a child at home, because the cost is too high. You need to pay a nurse, have a whole structure to fund probe for the ones who uses it, diapers, avoid bedsores, these things (P11).

For the reports, the professionals believe that many of these families' dropouts occurred by financial difficulties. Families who have children with chronic disease conditions are more financially vulnerable, and their costs are three times higher than healthy children. These children require increased family financial investment, because it possesses a range of needs that involve financial cost.¹⁵ In addition to the costs involved with supporting materials, transport and treatment, the demands resulting from the chronic condition interfere with parents' ability to remain in employment.¹⁶

Socioeconomic conditions influence health, housing, culture and material living conditions, family dynamics, as well as the way the care is provided to people with disability.¹⁷

The financial factor directly affects the family care of patients with a particular neurological disease, as it difficults even the access to health services.¹⁸ Factors such as family income affects the role of the mother for having the best resources to continue the treatment of her child, as well as seeking less

accessible treatment modalities. The authors also report that families with financial limitations have more difficulties to purchase materials necessary for the care and to access the health services, which could affect the treatment of children with cerebral palsy.¹⁹

For the fact that these patients are totally dependent and, consequently, their care are constant and complex, this can be considered a major stress factor to the caregiver, who, in the responsibility to a vital care, feel obliged to develop them not to be targets of criticism from the society.²⁰ As noted in the following lines, to the nursing staff is the lack of love that makes the family leaves the members in an institution:

Oh well, like I said, I think the lack of love saw. Lack of interest, love in your heart. The financial condition is part, but with willpower to fight I think get things right? Now the paramount is the love that the family has to have the love, affection, that is the paramount (P3).

[...] There is a case in which the person admitted her, I saw her coming, about 17 years ago, she died must 3, 4 years ago, I just saw the family bringing this patient, brought up in the lap, right? She was tiny and was left - then the family vanished, went to another city, even to find to say that she died was difficult eh, until they came, but would not come, to make the legal procedures body, right? (P4).

Shame, mainly older (P6).

Some, shame; others, lack of financial or emotional condition (P7).

The lack of knowledge about the disease and its treatment may also be a factor for the renunciation according to the statments. Elucidating the population about the disabilities may contribute to more positive attitudes towards these people, besides representing an important strategy for social inclusion.²¹

Prejudice is a social problem that causes embarrassing, unpleasant and limiting effects. In a society where the body can be compared to a commodity, and the differences are highlighted as lack or failure, deficiency can lead to denial.¹⁷

Caregivers need time to accept and adapt to the child with cerebral palsy demands. This situation requires extensive support from family and health professional, to face the circumstances that disability causes in the family dynamic.⁷ To effectively cope with the situation, future plans for the patient need to be reinterpreted, or abdicated, and the parental attitude should be reviewed, because the proactive role of parents contributes, greatly, to the treatment and rehabilitation of patients.¹⁷

The whole family context is affected by

the birth of a child with CP. To know the disease's complexity, the effects of the disease in the family and the patient should be considered.⁹ Only with further information about the disease, and its impact on children's lives, may the family have a better interaction with the child.¹⁷

Clarifying the population regarding disabilities contributes to more positive attitudes, besides representing an important strategy for social inclusion.²¹

♦ Category 3: Trying to compensate the family abandonment

The professionals speeches show their needs to compensate somehow the abandonment suffered by patients, either through his own work in nursing or posing as their own families.

I feel good, comfortable to take care of them and is an extra care that we can give to them, right? Since many of the family here do not even come and, as far as possible, we do what we can (P4).

I feel as if I am playing a familiar role, because these patients are already part of my life and I always try to give my best to them (P5).

Because these patients are totally dependent. If they are here is because the family in one way or another was unable to care for. Thus, I put myself in their shoes, right? [...] Here the "children" are like my own children, do you understand? (P11).

It is noteworthy how these professionals ensure the care and feel useful to what they do, because experience the reality of these patients - call them "children" for being dependent, and reveal how much they need attention, affection and care.

The nursing professional ends up getting used to the patient because it is a resident of the institution, then there is no turnover of interneers, building, therefore, a patient / professional bonding.²⁵ The nursing worker begins to regard him as a friend, a family member, a person with normal characteristics, who tries to make up for the absence of the family in the patient's life.

In a research with caregivers of children with PC, it is shown that the relation of these caregivers is a gratification reason for the maternal instinct and transformation of own personality.¹⁷

♦ Category 4: The importance of Family

When dealing with the family, all professionals interviewed believe in the importance of their participation in the care and monitoring of these patients, and show that affection and familiar presence make great difference in their development.

I think the family has a key role in monitoring these patients because it turns out that those

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who are accompanied by them has a different behavior (P1).

The family is essential to the development of the child; is the family that is the beginning of all remedies, joy, child's motor development (P2).

The family is paramount in these cases, all love, even not from the family, but from us, who feel that it is very good to the their development(P5).

[.....] Family is all (P6).

The family life is beneficial for anyone, once you have respect, love and affection (P7).

The family is very important, accompanies them, we realize that is patient, at least those who understand, are happy or show any reaction - the affection (P9).

The education and family support are the most beneficial aspects when it comes to a child with disabilities. The family plays the key role in the development of children with cerebral palsy and monitoring of patients with this diagnosis. In practically all accounts, the family appears with a huge significance in patient care with cerebral palsy.

The importance of family in the treatment of patients, especially those patients with cerebral palsy, is unquestionable because, in most cases, the family develops with the patient their own form of communication and care, which must be respected.²⁶ Family participation in the care of the child with CP motivates the development and a healthy life, but the family needs support and an organized social network.²⁷

The family, besides being the first social unit that the child knows, has a strong and important influence in determining the behavior and the formation of personality, enabling the individual survival process. The family plays a key role in the child rehabilitation process, especially in CP cases.^{15,27}

Given the importance of greater involvement and better preparation of parents for the care of children with disabilities, later works should search for literature publications produced in order to find their knowledge on the various aspects related to cerebral palsy and Down Syndrome.²¹ And nursing should be considered essential in the preparation and training of these families to better care for patients with CP.

FINAL REMARKS

The development of this research highlights that the nursing work with patients with cerebral palsy is engaging, in which are established strong emotional ties. It not only

consists of nursing care, but assistance that goes beyond, intertwined with emotional feelings and a need for compensation for the family abandonment suffered by these patients.

Feelings reported by professionals about their own work showed a not only professional, but also personal achievement. They believe in the assistance provided, and claim performing it with great satisfaction and devotion.

Nursing, when dealing with the care of the patient with cerebral palsy, has an important role not only in patient care, but also in education and awareness of both family and community about the understanding of this disease, intending to a better acceptance and inclusion of patients in the family and society.

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