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RESEARCH

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IMPLICATIONS OF LONG HOSPITALIZATION FOR CAREGIVERS OF CHRONICALLY ILL CHILDREN: THE ROLE OF SOCIAL WORK

Implicações da longa hospitalização às cuidadoras de crianças adoecidas cronicamente: atuação do serviço social

Implicaciones de la hospitalización prolongada para los cuidadores de niños con enfermedades crónicas: desempeño en los servicios sociales

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ABSTRACT

Objective: to describe the implications of the long period of hospitalization on social and psychological dimensions of caregivers of children with complex chronic health conditions. **Method:** qualitative research conducted with caregivers of chronically ill children in long-term hospitalization in a pediatric hospital from Bahia. Data collection was carried out between 23 February and 09 March 2021, remotely, by semi-structured interview. Content analysis was used to systematize the data. **Results:** Six caregivers participated in the study. Four categories of analysis emerged: Withdrawal from the socio-family support network; Psychosocial distress that permeates hospitalization; (De)Humanization of Care; and Importance of Social Work professional's performance. **Conclusion:** it was identified the need for a professional performance that attends the family in a comprehensive way, consistent with qualified confrontation to reduce the damage caused by the long hospitalization of the child, in order to enhance the humanization of care.

DESCRIPTORS: Caregivers; Child health; Chronic disease; Social work; Humanization of assistance.

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RESUMO

Objetivo: descrever as implicações do longo período de hospitalização às dimensões psicológica e social das cuidadoras de crianças com condições crônicas complexas de saúde. **Método:** pesquisa qualitativa realizada com cuidadoras de crianças adoecidas cronicamente em longa hospitalização em um hospital pediátrico na Bahia. A coleta de dados foi realizada no período entre 23 de fevereiro e 09 de março de 2021, remotamente, por meio de entrevista semiestruturada. Para sistematizar os dados utilizou-se análise de conteúdo. **Resultados:** participaram do estudo seis cuidadoras. E emergiram quatro categorias de análise: Afastamento da rede de suporte sociofamiliar; Dores psicossociais que permeiam a internação hospitalar; (Des) Humanização do Cuidado; e Importância da atuação do profissional de Serviço Social. **Conclusão:** identificou-se a necessidade de uma atuação profissional que atenda a família de forma integral, condizente com o enfrentamento qualificado à redução dos danos causados pela longa hospitalização infantil, no intuito de valorizar a humanização do cuidado.

DESCRITORES: Cuidadores; Saúde da criança; Doença crônica; Serviço social; Humanização da assistência.

RESUMEN

Objetivo: describir las implicaciones del largo período de hospitalización para las dimensiones psicológicas y sociales de los cuidadores de niños con condiciones crónicas complejas de salud. **Método:** investigación cualitativa realizada con cuidadores de niños con enfermedades crónicas en hospitalización prolongada en un hospital pediátrico de Bahia. La recolección de datos se realizó en el período comprendido entre el 23 de febrero y el 9 de marzo de 2021, de forma remota, a través de una entrevista semiestructurada. Para sistematizar los datos se utilizó el análisis de contenido. **Resultados:** seis cuidadores participaron del estudio. Y surgieron cuatro categorías de análisis: Retiro de la red de apoyo sociofamiliar; Dolores psicossociales que permeian el ingreso hospitalario; (Des) Humanización del Cuidado; e Importancia de la actuación del profesional de Trabajo Social. **Conclusión:** se identificó la necesidad de una actuación profesional que atienda a la familia de forma integral, coherente con el enfrentamiento cualificado a la reducción de los daños causados por la larga hospitalización de los niños, para valorizar la humanización del cuidado.

DESCRIPTORES: Cuidadores; Salud del niño; Enfermedad crónica; Servicio social; Humanización de la asistencia.

INTRODUCTION

The complex chronic health condition of children demands caregiver abilities, organized primary care network and advanced technological resources for life maintenance, which makes the process of returning the family to their home a time-consuming one.¹ The provision of these items determines the length of the family's permanence at the health care institution and can worsen the social distress due to the withdrawal from their support network, abandonment of employment, reduction or interruption of leisure time, overburdening of the primary caregiver, and fragilization of relationships.²

The discovery of a complex chronic disease usually frustrates the parents, since the idealized baby is different from the real one. Thus, the family needs to adapt to a new reality, offering assistance to enable the child's development, through recurrent and intense use of health services and technologies, in addition to access to multidisciplinary care.³ The professional must be able to provide family support, because the feeling of submission to norms and routines, plus the suffering of the child's complex chronic illness, demands the development of strategies to maintain the emotional health of these mothers.

Regarding the issues related to child illness, the care team needs to act through the use of soft technologies, such as embracement, active listening and humanization of care. Based on this, the present work presents as research question: What are

the implications of long period hospitalization on the social and psychological dimensions of caregivers of children with complex chronic health conditions? And as an objective to describe the implications of long period hospitalization to the social and psychological dimensions of caregivers of children with complex chronic health conditions.

The study is justified by the need to discuss issues related to the theme. The precarity of publications was noticed when searching for the descriptors "Social Service" and "Child Health" and "Chronic Disease" in the research platforms Biblioteca Virtual da Saúde (Virtual Health Library) and SCIELO. It is necessary to have more scientific studies on the subject, which is so incipient.

METHOD

Qualitative research, which aims to know the experiences of the subjects with the researched problem, emphasizing the understanding of the person's development processes and subjectivity.⁴⁻⁵ The study was conducted according to COREQ (COnsolidated criteria for REporting Qualitative research).⁶ The study took place in a philanthropic, pediatric hospital located in the Northeast of Brazil and the participants were caregivers of children hospitalized in a unit for complex chronic diseases, who met the criteria: being the child's mother and being hospitalized for more than ninety days.

Considering the prerogative of the World Health Organization (WHO) to keep social distance due to the current pandemic context by COVID-19, data collection happened remotely, between 23 February and 09 March 2021, by phone call. The interview was semi-structured, composed of closed questions referring to the socio-economic profile and open questions related to changes in the daily life since the child's birth, including their perception of the Social Work professional's role in the meantime.

The guiding questions were What has changed since the child's birth? Do you have other children and/or a support network? What feelings were aroused during the hospitalization and the coping strategies used?

The interviews lasted about 40 minutes and were recorded with the aid of a smartphone, capturing their speech integrally and been transcribed in full after that. The organization and analysis of the data came from the reading of texts related to the theme, seizing the cores of meaning originated by transversal reading. Then, the themes were grouped for final analysis.⁷

The research respected the ethical principles involving human beings defined in Resolution 466/12 and was approved on 29 September 2021 through protocol number 5.005.770.⁸ To ensure anonymity, the caregivers were identified with gemstone names.

RESULTS

Six caregivers of children with complex chronic health conditions participated in the study, as summarized in Chart 1.

The caregivers' reports about the implications of the long period of hospitalization for children with complex chronic health conditions were organized into the following representative categories:

Withdrawal from the socio-family support network

In the testimonies were reported feelings of missing family members, loneliness, and sometimes being abandoned due to the fact of being away from the rest of the family.

Sometimes I feel alone, far from my family. My son is the one who gives me strength to continue, I am here for him and I want to go back home with him. (Amethyst)

I have three other children, a girl who is ten years old and two boys, one is eight and the other is four. I have no relatives in Salvador, my support is my husband who stayed with my other children. I prefer to stay here; I don't feel safe with someone else taking care of him [...]. (Diamond)

I miss coming and going, here it seems that my life is stopped, far from everything and everyone. He can't receive visits, I have no one to come and stay with him, I feel abandoned. (Ruby)

Psychosocial distress that permeates hospitalization

The caregivers portray that the feeling of confinement, allied to the stress of the hospital routine that involves invasive and painful procedures, corroborates with the feeling of discomfort among the companions, who feel powerless in face of the child's pathology.

It's very sad to stay locked in here and not be able to go out, I can't see day or night, whether it's sunny or raining. It seems I'm not part of the world outside. (Crystal)

Since he was born, he has never been home, he doesn't even know his brother. And now I won't be able to work anymore, because I have to take care of him [...]. (Ruby)

Chart 1 – Characterization of caregivers of long-term hospitalized children with complex chronic health condition. Salvador, BA, Brazil. 2021

CODE NAME	SOCIODEMOGRAPHIC CHARACTERIZATION OF THE CAREGIVER
Amethyst	30 years old, her hospitalized child is one year and three months old, she has another one who is eight years old. Stable union, Catholic. She lives in the countryside in her own house, which does not have basic sewage system; her income comes from the government's Family Grant (Bolsa Família), plus the income from the genitor's sporadic work.
Pearl	45 years old, her hospitalized son is 16 years old, and she has three adult children. Single, Catholic. She lives in the urban area in rented property with complete infrastructure. She studied until the 5th grade of elementary school and receives the Continuous Cash Benefit (BPC), in the value of one minimum salary.
Crystal	25 years old, her son is 11 months old, and she has another one who is seven years old. Stable union, catholic, lives in the urban area in her own property with basic sewage system, interrupted her studies in the first year of high school. The family income comes from the government Grant (Bolsa Família).
Emerald	26 years old and her only hospitalized child is three years old. Single, Catholic. She lives in the countryside in her own property that has no sanitary sewage system. She finished high school and receives BPC due to her child's medical condition.
Ruby	30 years old, her only child is five months old and has been hospitalized since birth. Married, catholic, lives in the urban area in her own property that has basic sewage system, completed high school and worked under a formal labor contract before pregnancy.
Diamond	She is 30 years old, and her hospitalized son is two years old. She has three other children, a girl (10 years old) and two boys (4 and 8 years old). She says she has a stable union and has no religion. She lives in the countryside in her own property, with no sewage system, and has finished elementary school. The family income comes from government grant (Bolsa Família).

I am very afraid of leaving here without my son alive. I don't know if we are living one day more or less [...]. (Amethyst)

(De)humanization of care

It is perceived in the caregivers' speech that the care team can be seen as a motivating or demotivating factor, depending on the quality of the bond built.

[...] We are not well here, so having a person that cares about us is very good, I have been happy to meet many people from the team. (Crystal)

I already felt a lot of anger [...], mothers also need to laugh, distract themselves [...]. (Pearl)

In the hospital I feel a lot of sadness, anger, because the nursing technicians wake us up at 7am in the morning, asking us to get up and bathe the children. (Diamond)

The importance of social work

It is observed, by the statements, that the caregivers count on the intervention of social work, whether by embracing and listening, or even intermediating for the provision of financial assistance.

A The social assistant comes here, asks how I am, if I need anything, listens to me, gives me strength, speaks words that encourage me to move on, they do everything so that I don't feel alone. (Amethyst)

The social assistants helped me to get a grant from my township, thank God they pay the rent, every month the township sends (the amount) correctly. (Emerald)

[...] I like them because they always do activities at Easter, on Mother's Day and at Christmas. They always remember us, bring us a memory, make us feel special. (Ruby)

DISCUSSION

When considering the caregiver's individual, cultural, and psychosocial aspects, it is aimed that the multiprofessional team act with the principles of the humanization of care, through practices that involve the families' current conditions and the possibilities of overcoming them, stimulating the co-responsibility for the child's care. A study corroborates the need for changes, since human relationships at the most diverse levels contribute to a harmonious coexistence between professionals, patients, and family members.⁹

Being a companion during the chronic patient's hospitalization demands resilience from the caregiver for the long period of hospitalization. Thus, when the care is humanized, there may be a reduction of stress due to the period of hospitalization,

impacting the quality of care provided, as well as the well-being of those involved in the process, besides offering more security to caregivers after hospital discharge.¹⁰

The caregivers reported the feeling of abandonment and loneliness caused by the detachment from family, friends, and from the social support network. This occurs because of the magnitude of the maternal dedication to follow the hospitalization of their child. In this sense, many families that present similar situations, seek support through religious groups and congregations.¹¹

The caregiver's overload is related to the lack of family support, giving rise to an immense responsibility for the family unit when one of its members becomes ill.² In case there is no segregation of roles, there is a great risk of the main caregiver becoming physically and emotionally ill.

Social pains are widespread pains that affect individuals related to their health/illness condition, socioeconomic, housing, access to resources, services and policies, family organization, social support network, and influence health care.¹² Chronic illness has important repercussions on the families' lives and dynamics, from the weakening of marital relations, to the loss of professional and social ties.² The consequences of these ruptures can generate financial imbalance, leading to the interruption of leisure time, increasing the caregiver's burden.

In addition, the family suffers for the lived and the unlived, the fear of what may happen to the hospitalized patient in face of chronic pathology and the imprecision of information provided by medicine about the diagnosis and therapeutic possibilities.¹²

It is undeniable that the challenges faced also contribute to personal growth and the strengthening of bonds between family members, and can positively impact the child's treatment.¹¹ Chronic diseases require a long period of supervision or care, besides being permanent, these require minimizing pain, suffering and family burden, maximizing the child's development and time out of hospital, relying on home care.¹³

To deal with the complexity of chronic diseases in children, it is necessary to have the support of a multiprofessional team that performs procedures and/or techniques on children, respecting the particularity of each patient and their life context.¹⁴

Another relevant point is humanization, because it is understood as the valuing of different subjects involved in health production process: users, workers and managers.¹⁵ When it comes to the humanization of care, it focuses on the assistance offered to the patient's family, in order to provide a welcoming and sensitive environment to emerging unique issues. The unit in which the study was carried out meets the precepts of the humanization of care from the proposal of contributing to the patient's return home and living with his/her family, from the training of the main caregivers and articulation with the network for comprehensive support to the child.

When considering the feelings that permeate a long-term hospitalization, it is important that the multiprofessional team works daily with the patient and his/her family, maintaining a harmonic and humanized relationship. In this way, pain and

suffering, whether physical, emotional, or spiritual, experienced by mothers can be prevented and relieved. According to the author,^{16,8} humanization can be understood as: a form of assistance that values the quality of care from a technical point of view, associated with the recognition of the patient's rights, subjectivity, and cultural references. It also implies the valorization of the professional and the intra and inter-team dialogue.

The caregivers indicate that the care team can be seen as a motivating or demotivating factor, depending on the quality of the bond built. Thus, it is worth mentioning that when there is empathy between professionals and caregivers, the coexistence in the institutional space becomes healthier, favoring the caregivers' participation and involvement in the assistance and in the relationship with the team. Thus, it can be said that understanding in the process of caring is essential, thus, to put oneself in the other's shoes is first to know who one is and then to know what one is capable of.¹⁷

Caregivers also go through a time of uncertainty and anguish at the possibility of death,¹⁸ needing the support of a qualified professional. Therefore, it suggests the formation of therapeutic groups with family members so that they can put their emotions into words and share feelings and experiences with others who are going through the same situation.

It is important to emphasize that health professionals who work with children with chronic illness need to be able to provide humanized care to the caregivers. A review study signals the need to think of strategies to sensitize health professionals to establish a relationship with the caregiver; these actions contribute to the quality of care for the child.¹⁹

Social work professionals act in favor of the caregivers' well-being, being available both to welcome and to strengthen the patient's support system, in order to contribute to improving the family's quality of life. These professionals aim to know the patient/caregiver's socioeconomic and cultural profile in order to identify the limitations and possibilities that influence the child's treatment and dehospitalization. From an approach focused on the totality of the human being, the integrality of the subject is appropriated, whose social intervention must consider the aspects related to symptoms of physical, social, emotional, and spiritual nature.²⁰

Thus, the family's support network and possible conflicts that may interfere in the caregiver's well-being during the hospital stay and/or in the quality of care to the patient after returning home are inserted in this context.²¹

The social assistant is considered a professional with a sociopolitical, critical, and interventional character and has as its main objective to intermediate actions so that individuals have access to citizenship, therefore, he/she uses instruments that articulate with the theoretical-methodological, ethical-political, and technical-operative dimensions in the search for the realization of the rights of the user population.²² Seen as an intermediator

between social policies and users, it is a professional committed to ensuring access to and quality of the services provided, playing the role of educator in the health-disease process and helping to rescue the dignity of the patient's life and death conditions.²³

One of the actions of this professional is the articulation with the competent bodies in order for the chronically ill patient to have access to the income transfer benefit, called *Benefício de Prestação Continuada* (Continuous Cash Benefit), which consists of one minimum wage, when considering that the child's main caregiver cannot work due to the need for full-time assistance to the child. This aid is granted based on predetermined socioeconomic criteria, making it necessary to know the profile of each family. It is also part of the dynamics of integral protection, reporting to the competent organs when violations of rights and/or potential cases of violence are identified.²⁴

Considering this, it can be said that it is an indispensable category due to the fact that it knows the family's sociocultural reality, its possibilities and limitations and intervenes aiming at "the uncompromising defense of human rights".²⁵

The unit where the study was conducted intends to train caregivers by intermediating with the network in order to offer comprehensive care in its territory, so that safe dehospitalization can be achieved. Home care is a form of health care provided at the patient's home, which is characterized by the provision of a set of actions to promote health, disease prevention and treatment and rehabilitation, ensuring the continuity of comprehensive health care.²⁶ It is necessary that the home has adequate physical infrastructure for home care, including a supply of drinking water, electricity, easy access to communication, as well as an airy environment.²⁷

Thus, it is clear that the work of the Social Work professional has the objective to know and act on the conditioning and determinants of health through the articulation with the network. The intersectoriality is indispensable, starting from the awareness that the health sector alone cannot respond to the complexity of the demands of the integral being.

Therefore, it is important to point out that the municipality and the state are responsible for providing health professionals for on-site care, supplying inputs for the maintenance of care, and, regarding the availability of a Mobile Emergency Care Service (SAMU) with advanced support and a pediatric hospital with an intensive care unit to respond to complication cases. The Social Work professional must be the intermediary between the user and the public policy, aiming at the realization of the social rights of the public assisted.²⁵

The main contributions of this professional include the search for the quality of care during the stay in the hospital unit, aiming at knowing the dissatisfactions and the possibilities of coping, and the articulation with the municipal, state, and federal support network, in order to help the caregivers, facing the complexity of the clinical and social context experienced.

CONCLUSION

The study concluded that the implications of the long hospitalization for the caregivers of children with complex chronic diseases can lead to negative aspects such as: distance from family members and from the social support network, feelings of sadness, loneliness, among others. However, the role of Social Work professionals supporting caregivers through actions that enable welcoming, sensitive listening and valorization, besides contributing to the safe discharge of the patient, such as intermediation with public agencies, is highlighted.

This study is limited because it was carried out in only one unit of a single hospital, thus not allowing the generalization of results.

As implications for future research, this study aims to contribute to the knowledge of pediatric professionals about chronic illness in children and the long period of hospitalization, in addition to raising their awareness through reflection on their professional practice.

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