ORIGINAL ARTICLE

Caregivers' perception of the experience of caring for family members and the relationship with the professional team in the context of hospitalization

Percepção dos cuidadores sobre a experiência de cuidar dos familiares e a relação com a equipe profissional no contexto da hospitalização

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ABSTRACT: The presence of caregiver/relatives in the hospital enhances the patients' improvement. However, it may also expose the caregivers to complex situations of frailty and vulnerability. Objective: to understand and analyze the caregivers' perception of the experience of caring for family members and their relationships with the professional team in the context of hospitalization. Methods: qualitative exploratory study, conducted through transcribed interview and documentary research between August 2014 and July 2016. For the analysis, the Discourse of the Collective Subject method was adopted. Results: 22 caregivers participated, mostly women over 60 years of age. Half (11) of these caregivers had some professional activity, and 13.63% (3) interrupted them to care for the sick relatives. The Discourses of the Collective Subject indicated emotional distress and physical overload in the caregivers due to the accompaniment to the family member under hospitalization; caregivers acknowledged the team's actions; however, they described difficulties in understanding the guidelines offered. Conclusion: we indicated the need for devising management and care strategies directed to caregivers, to ensure partnership in patients' care and access of family members to a humanized care.

KEYWORDS: Caregivers; Relatives; Hospital care; Humanization; Occupational Therapy; Patient Care Team.

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RESUMO: A presença do cuidador/familiar no hospital é considerada um fator que potencializa a melhora do usuário, no entanto, também pode ocasionar a exposição do cuidador a situações complexas, de fragilidade. Objetivo: Conhecer e analisar a percepção dos cuidadores sobre a experiência de cuidar dos familiares e a relação com a equipe profissional no contexto da hospitalização. Metodologia: Estudo de caráter qualitativo exploratório, realizado por meio de entrevista e pesquisa documental entre agosto de 2014 e julho de 2016. Para análise, foi adotado o método do Discurso do Sujeito Coletivo. Resultados: Participaram 22 cuidadores, na maioria mulheres, acima de 60 anos. Metade desses cuidadores possuíam alguma atividade laboral e 13,63%, as interromperam. Os Discursos do Sujeito Coletivo assinalaram desgaste emocional e sobrecarga física dos cuidadores decorrente do acompanhamento do familiar na hospitalização; reconhecimento das ações da equipe, contudo, dificuldades dos cuidadores de apropriação das orientações oferecidas. Conclusão: Indica-se a necessidade de construção de estratégias de gestão e atenção direcionadas aos cuidadores, para garantir a parceria dos mesmos nos cuidados dos usuários e o acesso a uma atenção humanizada.

DESCRITORES: Cuidadores; Familiares; Atenção hospitalar; Humanização; Terapia ocupacional; Equipe de assistência ao paciente.

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INTRODUCTION

Caregiving refers to being responsible for the care of another, whether related to the maintenance or quality of life of people who, due to different problems, feature partial or integral dependency[1]. In this sense, caregiving involves a broad range of actions – of commitment, concern, attention, and good treatment – that "[...] emerges according to the importance of the cared subject to the other – the caregiver"[2].

Thus, caring implies in the presence of a person who formally or informally takes care of the other. Formal caregivers have a specific professional knowledge and are usually paid for their services, while the informal caregiver learns by practice the proper way to provide care[3]. The informal caregiver can be a family member or friend of the person who needs care, and assumes this role without the obligation of a contract[1].

Caregivers can act in household environments, in the community and institutions. In the event of hospitalization, for example, the presence of caregivers/relatives in the hospital is recognized as a factor that enhances the patient's improvement[4] and assists in the reduction of feelings concerning the rupture with activities that are part of the person's routine. However, this presence can also expose the family to frailty and vulnerability circumstances. After all, " literature shows that caregiving is not an easy task as it involves dealing with human limits, with life, illness, and with death itself [...]"[5]. These are elements that surround the hospital setting and, generally, remit the caregiver to the deprivation of social life as well as of freedom to perform self-care activities[5,6,7].

This reality points to the need for actions directed to caregivers/relatives because they usually have no preparation or support to deal with the feelings and obligations coming from caregiving[2]. Moreover, these people also experience changes in their routines, which start revolving around the hospitalized person and the hospital routine.

In response to this need, and recognizing the importance of the caregivers' social role, the National Policy of Humanization (NPH) proposes the inclusion of open visitation in hospital, aiming to ensure the patients' comfort and participation of the family in the care during the hospital stay, as well as its continuity after discharge[8]. The NPH also suggests that health teams should provide quality care, associating new technologies with hospitality and with the development of care environments to all subjects circulating in those spaces, both patients and family[8].

Such policy recommends that teams' and health equipment management's actions should contribute to a humanized and integral practice, based on the development of a comfortable ambience and on understanding the patients, their life context, relationships, culture, active participation in the treatment, besides promoting health and autonomy[4,9,10,11].

This understanding is fundamental because the hospital routine and its organization may generate stress and exacerbate the patient's condition[12], with important reflexes on the caregiver's health. Therefore, the Occupational Therapy (OT), as a field of knowledge and a producer of interventions in health, has a rich and vast repertoire of technologies, which can be added to a humanized care directed to the needs and cultures of the patients under hospitalization. In other words, it can intervene in functional, organizational, emotional and/or social demands of patients, as well as in the development or recovering of healthy experiences, aiming at the return of their home activities and social life[12].

Hospital discharge, in turn, is regarded by professionals as an important moment for the care continuity because it involves several team procedures, which should be focused on the patients' needs, to encourage self-care, and on the caregivers' needs, to create co-responsibility and advise them on the care of their families when returning to their homes[13]. After discharge, the caregiving situation differs from that in the hospital, since it will be developed according to the patient's culture and reality, as a transitional process from hospital care to home care[14].

Based on these considerations and looking to contribute to the humanization of hospital care, this study aims to understand and analyze the caregivers' perception of the experience of caring for the family members and their relationship with the professional team in the context of hospitalization.

METHODS

The exploratory qualitative study is part of a broader research financed by the São Paulo Research Foundation and was approved by the Research Ethics Committee under protocol No. 365/2013, as determined in Resolution No. 466/2012 of the National Health Council. After the presentation of the research objectives and the participation agreement, all the participants signed an Informed Consent Form.

The study was conducted at the University Hospital of the University of São Paulo (HU-USP), which is characterized by medium-complexity care, with relevant action in the integration between primary and tertiary care. Medium-complexity medical care stands out for the execution of specialized procedures performed by high school, college and technical level professionals and therapies[15], among other procedures provided for at that level of assistance. Therefore, the HU-USP, while a teaching hospital, has a multidisciplinary team that aids from different professional and academic training programs.

In this study, the participants were caregivers/relatives of patients hospitalized at the Clinical Medical Infirmary of HU-USP, who were assisted by OT and other professionals, from August 2014 to March 2016. There was also inclusion of caregivers/relatives of the patients attended by the OT, who visited the patient at the time scheduled by the hospital or in the usual caregiver visit period. Given the patients' short hospitalization period, there was exclusion of: caregivers/relatives who were not assisted by the OT; those who were not in the infirmary during the visiting hours or in the usual visit period after two contact attempts, , those who were discharged before data collection; and those who did not agree to participate..

Data collection procedures comprised transcribed interview and documentary research. The interview features four open questions, which sought to identify the experience of caregivers during their relatives' hospitalization regarding doubts, difficulties, and requirements related to: 1) care services offered to the patient and the adaptations in the caregiver's routine; 2) the relationship established with the professional team; 3) the relationship established with occupational therapy; 4) orientations for hospital discharge. The interviews had an average duration of 30 minutes.

To record the interviews' data, notes were taken during and immediately after their endings, in order to reconstruct the observations identified and the answers given by the interviewees. For Ludke and André[16], the transcribed interview is a suitable data collection procedure since it provides the interviewer with prior selection, interpretation, and perception of the positive and negative emphases made by the interviewees. Such procedure also enables the participants' free expression, as they do not have to worry about the recording of undesirable statements[16], which can make them insecure about the possible influence it may have on the care provided by the hospital.

Thus, the choice for the transcribed interview showed to be effective in building a more comfortable environment in the infirmary during the visiting period. However, it should be highlighted that this procedure requires a certain skill of the interviewer to simultaneously conduct the interview and transcribe responses and comments.

The documentary research, in turn, which is understood as the analytic treatment of any written material as a source of information about the human behavior[16,17] was carried out from the analysis of hospital records and OT specific records.. In these documents, sociodemographic and clinical data of the cared population and their respective relatives were collected.

To analyze the interviews' content, Lefrève and Lefrève's Discourse of the Collective Subject (DSC) method[18] was used. This method intends to organize the testimonies obtained in interviews in form of discourses, which seek to represent the collective's experiences and feelings and produce an effect of speaking collectivity on the reader [18].

The discursive strategy used in the DSC allows making "[...] a particular social representation clearer, a set of representations that characterizes imaginary data on a given theme" (p.19)[18]. Thereby, the DSC enables the knowledge present in common sense to be shown, expressed through opinions and manifestations[18]. In this study, specifically, the DSC allowed the gathering of fragments concerning the caregivers' perception of the experience of caring for the patients and the relationship established with the professional team during the hospitalization, thus producing a discourse that is representative of their collective experience.

According to the method, the different discourses collected were transformed into similar discourses, expressed in the first person point of view and organized from methodological figures: the central idea and the key-expression. For this purpose, the following steps were performed: selection of central idea to objectively identify and describe the meaning of the discourse; selection of key-expressions, consisting of excerpts of the testimonials that represented the discourse meaning; assemblage of the discourses from the key-expressions, according to their similarities and equivalencies; and presentation of the DSC in italics, in the singular form of first person point of view[18].

RESULTS

Twenty-two caregivers/relatives of hospitalized patients assisted by OT participated in this study (Table 1). The caregivers were mostly women, representing 17 participants (77.27%), and nine (40.90%) were above 60 years of age. Only two (9.09%) out of the 22 caregivers did not have a direct kinship with the patient. Eleven (50%) of them had a support network of friends and family to share care activities during the patient hospitalization and subsequent discharge. Regarding educational level and professional bonds, 21 (95.45%) caregivers attended school, 11 (50%) exercised a professional remunerated activity, and three (13.63%) were away from their working activities to accompany the relative at the hospital.

Table 1 – Profile of caregivers/relatives of the patients who were accompanied at the Clinical Medical Infirmary of the HU according to gender, age, education, emotional bond, and professional status. São Paulo, 2016

Gender	**Number**	**Percentage (%)**
Female	17	77.27
Male	5	22.72
Age	**Number**	**Percentage (%)**
≤ 19 years	1	4.54
20 ≤ 39 years	7	31.81
40 ≤ 59 years	6	22.72
60 < years	9	40.90
Educational level	**Number**	**Percentage (%)**
Illiterate	1	4.54
Elementary School	11	50
High School	10	45.45
Higher Education	0	0
Emotional bond	**Number**	**Percentage (%)**
Spouse	6	27.27
Mother	1	4.54
Father	1	4.54
Sister	4	18,18
Brother	2	9.09
Daughter	6	27.27
No kinship	2	9.09
Professional status	**Number**	**Percentage (%)**
Formally employed professional	5	22.72
Self-employed professional	6	27.27
Time away from work	3	13.63
Retired	6	27.27
No professional bonds	2	9.09

Regarding patients' profile, a distribution by gender and age that is similar to those of the caregivers can be observed. Most were women, representing14 participants (63.63%), and 10 (45.45%) presented ages equal or superior to 60 years. Among the conditions that led to their hospitalizations, the most recurrent were Circulatory System Diseases, with 36.36%, followed by Genitourinary System Diseases, with 18.18% (Table 2). The functional consequences of these diseases have been identified by the caregivers as the most worrisome topics, due to the patients' dependency on performing activities of daily living and instrumental activities of daily living (ADLs and IADLs, respectively).

Nevertheless, in OT medical records it was observed that most of the users, representing 16 patients (72.72%), had some degree of dependency on ADLs and IADLs: six (27.27%) were partially dependent, 10 (45.45%) were dependent, and six (27.27%) were independent, according to the records of the Barthel Index (IB) evaluation.

Concerning the interviews' content, it was possible to identify that open questions facilitated the free expression of the interviewees and, therefore, allowed the production of representative discourses, as provided for in the DSC method[18], regarding the reality experienced by the caregivers during the hospitalization of a family member.

In this set, six central ideas (CI) that corresponded to six DSC (Chart 1) were identified. The first two CIs focused on the confrontation related to the feelings and obligations arising from the caregiving, and the routine adaptations experienced by the caregivers: 1st CI - emotional distress: *this situation is not easy!*; 2nd CI - Overload and routine changes: *my mind is racing with everything I have to solve.* The 3rd CI, in turn, highlights the acknowledgment of the care provided by the professional team: 3rd CI - Professional team: *everybody helped!* The 4th CI reveals the difficulties of the caregivers in understanding the orientations provided by the professional team: 4th CI - Communication difficulties: *I struggle to understand what they say!* The penultimate CI presents the caregivers' perception of the contribution of the performance of OT during the hospitalization: 5th CI - Occupational Therapy: *it taught me how to do things more independently.* And, lastly, the 6th CI points to the importance of the hospital discharge in the caregiving continuity and organization of the extra-hospital routine: 6th CI - Hospital discharge: *from now on it must be a new life!*

Table 2 – Sociodemographic and clinical profile of the accompanied patients at the Clinical Medical Infirmary of the HU according to gender, age, ICD-10. São Paulo, 2016

Gender	**Number**	**Percentage (%)**
Female	14	63.63
Male	8	36.36
Age	**Number**	**Percentage (%)**
≤ 19 years	1	4.54
20 ≤ 39 years	6	27.27
40 ≤ 59 years	5	22.72
60 < years	10	45.45
ICD-10	**Number**	**Percentage (%)**
Circulatory System Diseases	8	36.36
Genitourinary System Diseases	4	18,18
Some Infectious and Parasitic Diseases	2	9.09
Digestive System Diseases	2	9.09
Musculoskeletal System and Connective Tissue Diseases	2	9.09
Skin and Subcutaneous Tissue Diseases	1	4.54
Nervous System Diseases	1	4.54
Ear and Mastoid Apophysis Diseases	1	4.54
Mental and Behavioral Disorders	1	4.54

Chart 1 – Discourse of the Collective Subject regarding the caregivers' perception of the experience of caring for family members and the relationship with the professional team in the context of hospitalization. São Paulo, 2016

1st CI - emotional distress: this situation is not easy!
DCS 1 - My relative has only me and I'm tired. Everything is very heavy! This situation is surely not easy, it's hard for me to see him like that, my heart even hurts! I wasn't expecting this, it was shocking, but I'll take care of it! After all, I'm not ready to see him in a coffin! I've already lost other people and it hurt me deeply. I don't want to go through that again! It's very hard!
2nd CI - Overload and routine changes: my head is racing with everything I have to solve!
DSC 2 - My head is racing with everything I have to solve! But I stopped doing everything when I heard my relative wasn't fine, I left everything behind, stopped working and taking care of my children. After all, I have to help with everything: bathing, walking, feeding. I can't do anything else just for me anymore, I don't sleep well, don't eat well, I can't do anything right... I miss everything at home, but now the only thing to do is to take care of him!
3rd CI - Professional team: everybody helped!
DSC 3 - Everybody took very good care of my relative, the nurse technicians helped a lot. The nutritionist, the physiotherapist, the therapist, and the psychologist as well. The nurses seem to be family, and they even worry if I've eaten or not. The doctor is also very good; he's done several tests... a lot of things. I even thought my relative wouldn't leave the hospital, but it all worked out in the end! He has been very well oriented, and so has my family!
4th CI - Communication difficulties: I struggle to understand what they say!
DSC 4 - A lot of people passed by this room, I can't remember everything. A lot of doctors, nurses, physical therapists. It is difficult to remember all this, I'm very tired. I struggle to understand what they say, but it's too much!
5th CI - Occupational Therapy: it taught me to do things more independently.
DSC 5 - The therapist is a very nice person. Very loving. She taught me some exercises for us to do at home, so my relative's arms won't be stiff, and how to move his hand and massage him. She also taught how he can do things more independently. She told him to eat by himself, bathe by himself. Several tips on what is and what isn't important; she told him to do things that won't tire him too much, and even explained how to do the exercises to prevent falls. In short, the therapist was very attentive; she listened to me, read the Bible with us and brought some crochet for my relative to do. Certainly she was an angel that came my way!
6th CI - Hospital discharge: from now on it must be a new life!
DSC 6 - The professionals will discharge him, and I'll accompany him. They will explain how "to put him on the dialysis machine", also informing as to the medication. I haven't even acquired the bathing chair, I'm not ready for that, but when my relative is discharged, I'll organize myself on to it. I also have to move from my apartment because of the stairs, but what matters now is that he is coming back home! After all, the fight begins now; from now on it has to be a new life, it is a new life! But we'll see, in theory things work like a charm!

DISCUSSION

The profile of caregivers/relatives found in this study was similar to those registered in literature[13]. Most of them were older women, workers, with a direct kinship with the hospitalized patients, and the majority had some help from a support network of friends and family, with whom they could share the caregiving, since part of the patients presented a significant degree of dependency for ADLs performance.

Such caregivers' profile can be compared to the current changes in the familiar institution[13], which are related to the increased number of older adults leading and caring for the family members, as 40.90% of the participants were 60 years of age or older. It can also be related to the current place of women in society, occupying distinctive roles (worker, wife, boss, political representative, among others) that are not only connected with home environments and family care[13]. Another significant aspect is the decreased number of children per couple, which leads to a decrease in the family support network, as 50% of the caregivers in this study reported to count on help of friends and family.

Thus, the characteristics of the caregivers - gender, age, assignments diversity, decreased support network -, in addition to the responsibilities of accompanying the ill relative, can influence the way they present themselves in the hospital and relate to the sick patient. Namely, it influences on their demands in the hospital environment. Therefore, to meet the different needs and requirements that arise in the hospitalization process[5], the caregivers must be considered as subjects who need care by the professional team and the service management, aiming to produce more integral, humanized and hospitable health practices [4].

Emotional distress: *this situation is not easy*

The experiences of caregivers in the hospital can be stressing events[5], because of the exposure to frailty and vulnerability circumstances. Those can become challenging events and "[...] require resources and efforts for coping and adapting to the situation, as well as contributions to a smooth functioning of the family system when one of its members gets sick" (p.4591) [19]. This can be seen in: *I wasn't expecting this, it was shocking, but I'll take care of it! (DSC 1).*

Having said that, it is observed that the disease permeates several dimensions of the family organization (emotional, social, and cultural), reverberating for long or short periods in these people's lives[19], who, due to the hospitalized relative, expose themselves to extreme situations. Situations that can be related to illness, death, rupture of the usual routine[5], and that reaffirm the importance of implementing humanization, listening, and hospitableness in hospital practices, as follows: *I've already lost other people and it hurt me deeply. I don't want to go through that again!* (DSC 1).

In addition, assuming the caregiving role implies the construction and redefinition of the bond with the cared subject and, consequently,the elaboration of a "self" caregiver, sensitive to the needs of others, or rather saying, a "self" that purports to feel the hospitalization process and the suffering of the afflicted relative. The absence of such availability added to the lack of previous experiences with hospital care and concerns with the sick relative can favor the emergence of vulnerability feelings in the caregiver[19]. This can be observed in: *This situation is surely not easy, it's hard for me to see him like that, my heart even hurts!* (DSC 1).

Overload and routine changes: *my head is racing with everything I have to solve*

Caring for others can, in some cases, make the caregivers to neglect their own care, their wishes, and needs, and develop mixed feelings, both positive and negative[13,20]. Psychic conflicts, including fear, fatigue, irritation, in addition to the uninterrupted care, lead to overload[20], such as *I can't do anything else just for me anymore, I don't sleep well, don't eat well, I can't do anything right. [...] but now the only thing to do is to take care of him!* (DSC 2).

The concept of overload related to care can be understood as a set of responsibilities and feelings arising from the caregiving, which is often interpreted as a burden in the life of caregivers, an incumbency of risk condition to which these people are exposed[21]: *My head is racing with everything I have to solve!* (DSC 2) The experiences could be observed in this study when the participants associated caring responsibilities with cancellation in their living or working plans: *[...] I stopped everything when I heard my relative wasn't fine, I left everything behind, stopped working and taking care of my children* (DSC 2).

Thus, it is important to consider that the value and meaning of care might be influenced by many conditions, which implies in determining the place this activity takes up in the life of caregivers, how these people relate to their responsibilities, and how they share the caregiving activities with friends and family. Among the conditions that influence the meaning of care, the patient's dependency degree, registered in this study from the evaluation of the Barthel scale, was a relevant aspect in the relationship between caregiver and patient, as follows: *After all, I must help with everything: bathing, walking, and feeding (DSC 2)*.

Professional team: ***everybody helped!***

Given the complexity of caring, it is necessary that professional teams evaluate how they understand the caregivers in the hospital, as they are a growing population with their own emotional and organizational demands. Such demands may impact their relationships with patients, institution, and the very professionals who assist them. Thus, they indicate these people need help not only to take care of the patients but also to promote their own health and well-being[13].

In this sense, it is necessary that professionals and managers of hospital services consider the inclusion of caregivers in the care scope and provide professional and structural resources. For this, we highlight the importance of the teams, as far as possible, knowing the caregivers, their network of friends and family, the relative's needs, the disease characteristics, the essential guidelines for care after the patients' returning home[13] and, especially, acting in an integrated and articulated manner with the services network to plan the hospital discharge.

With these goals and recognizing that health demands permeate several areas of knowledge, the professional practice must be thought out in an articulated and integrated manner, developed by a team of professionals instead of by only one professional[22]. To this end, the multi-professional team should be understood as the cornerstone of the integrated "doing", and the relationships in it, between the multiple care agents, must be guided by reciprocity[22] to produce a more humanized and resolutive care.

We identified that the study participants, when referring to the assistance offered in the HU-USP, considered the care and assistance as multidisciplinary stances, coming from the orientations of several professionals, physiotherapists, nutritionists, psychologists, occupational therapists and speech therapists, which points to a perception of this care as diverse and responsible. Such can be seen in: *Everybody took very good care of my relative [...]. He has been very well oriented, and so has my family!* (DSC 3).

Communication difficulties: ***I struggle to understand what they say!***

Although the caregivers acknowledged the care offered by professionals, communication was identified as a challenge to be faced by the team's actions and service management. After all, the difficulty in understanding the orientations offered by professionals may compromise the preparation and continuity of the patients' care after hospital discharge[23], as described: *It is difficult to remember all this, I'm very tired. I struggle to understand what they say, but it's too much!* (DSC 4).

This difficulty may be related to the caregiver's cultural, social, emotional, and psychological factors, which sometimes make it impossible for them to gather and assimilate resources so as to understand the orientations given by professionals. It can also be associated with institutional aspects of the work – professionals' workload, short time of the patient in the hospital, and institutional routine – that may compromise the communication between professional staff and family members. This is exemplified in: *A lot of people passed by this room, I can't remember everything (DSC 4).*

To face the difficulties concerning the integration between care and caregivers' understanding of orientations, the NHP has highlighted the importance of changes in health actions, advocating the overcoming of existing frontiers between different knowledge[9] and, consequently, the integral care. In order to achieve that, it proposes that health care should be tied to the shared responsibility of the diverse actors in the Unified Health System (SUS), to the construction of the bond, to the hospitableness, and to the guarantee of the patients' and family members' rights[9].

Occupational Therapy: ***it taught me how to do things more independently.***

Concerning the actions of the OT in the HU-USP, they were, in the perception of the participants, based on listening and comforting interventions, which sought to consider values, religions, and cultural habits[11], as the excerpt: *[...] the therapist was very attentive, listened to me, read the Bible with us and brought some crochet* *for my relative to do* (DSC 5). Also, the contributions of OT professionals, according to the caregivers, covered techniques and orientations for reducing symptoms, increasing comfort, and developing skills to perform activities: *[...] taught me some exercises for us to do at home [...], taught me how to move his hand and massage him. She also taught how he can do things more independently* (caregivers' perception emphasizes the diversity of OT actions and the importance of bringing back healthy experiences and abilities to continue the activities and the care after returning home[11,12], as follows: *She told him to eat by himself, bathe by himself. She gave several tips on what is and what isn't important, told him to do things that won't tire him too much [...]!* (DSC 5).

Hospital discharge: *from now on it must be a new life*

Hospital discharge was emphasized by the caregivers as a challenge, due to the care responsibilities to be carried out at home: *The professionals will discharge him, and I'll accompany him. They will explain how "to put him on the dialysis machine", also informing as to the medication* (DSC 6); and due to the changes needed after discharge: *The fight begins now, from now on it has to be a new life, it is a new life!* (DSC 6). Caregivers also mentioned insecurity as to the lack of family organization for the discharge, related to the acquisition of adapted equipment and management of time and resources, as the excerpt: *I haven't even acquired the bathing chair , I'm not ready for that, but when my relative is discharged I'll organize myself on to it* (DSC 6).

Hospital discharge is a specific transition of health care, from hospital to home, from continuous assistance to family care. This requires from the hospital professional a planning that reconciles orientations directed to the patients' needs, preferences, and clinical status, and requires resources from the caregivers/relatives[9,13]. Also, since the hospital is a place of sojourn, it is recommended that professionals should direct attention as from the beginning of hospitalization to the evaluation and preparation of the discharge, through orientations to patients and relatives[24].

Therefore, as identified in this study, there is a need for supporting caregiver/relatives as to ensure a partnership in the patients' care, as well as building an integral, humanized, and hospitable care to all subjects circulating in the hospital service. However, this necessity is still a challenge for SUS, which justifies studies on this topic.

CONCLUSIONS

In the event of hospitalizations, patients' caregivers/relatives were susceptible to physical and emotional overload, stress, and disruption of their life routines due to the responsibilities they have. Also, although they acknowledged the care offered in the HU, both by the multi-professional team and by the OT, as diverse and very good, they expressed uncertainty and difficulties in understanding and retaining the orientations, especially those regarding the continuity of care after hospital discharge.

These circumstances point to the need for transformation of the caregivers' understanding within the hospital institution, so they can be recognized as partners in the patients' care and, also, subjects for provision of humanized care.

This study had as limitation the fact it was conducted with a restricted sample of caregivers. However, we believe this study can raise awareness among the professionals working in hospitals as to the importance of caregivers/relatives during the hospitalization, and stimulate studies on the subject.

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