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EXPERIENCES OF FAMILY CAREGIVERS DURING HOSPITALIZATION: THE BEGINNING OF OLD-AGE DEPENDENCY

VIVÊNCIAS DE FAMILIARES CUIDADORES EM INTERNAMENTO HOSPITALAR: O INÍCIO DA DEPENDÊNCIA DO IDOSO

VIVENCIAS DE FAMILIARES CUIDADORES EN INTERNACIÓN HOSPITALARIA: EL COMIENZO DE LA DEPENDENCIA DEL ANCIANO

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ABSTRACT

Objective: to understand the beginning of family adaptation to the situation of a disabling disease in self-care during hospitalization. **Method:** a descriptive exploratory study of qualitative approach, based on a phenomenological design. Data were obtained through semi-structured interviews conducted at three times. The participants were intentionally grouped according to their genogram, considering the total number of family caregivers of patients who became dependent, hospitalized in the medical service of a hospital in northern Portugal. **Results:** the situation in question is experienced by family caregivers with feelings of fear and powerlessness, causing significant changes in their personal, labor and social life, with repercussion in family functioning. **Conclusion:** in caregiving, the relation is still individual-centered, and the family is seen as a unit that can be divided into parts. **Descriptors:** Self-care; Hospitalization; Caregiver; Family; Nursing.

RESUMO

Objetivo: compreender o início do processo de adaptação da família à situação de doença com dependência no autocuidado em internamento hospitalar. **Método:** estudo exploratório-descritivo, de abordagem qualitativa, aproximando-se da fenomenologia. Os dados foram produzidos a partir de entrevista semiestruturada, em três momentos. Os participantes foram agrupados intencionalmente a partir do genograma, considerando-se o número total dos cuidadores familiares de doentes que se tornaram dependentes, internados no serviço de medicina de um hospital do norte de Portugal. **Resultados:** a situação em questão é vivenciada pelos cuidadores familiares com sentimentos de medo e impotência, gerando mudanças significativas em sua vida pessoal, laboral e social, com repercussões no funcionamento familiar. **Conclusão:** no processo do cuidar, a relação estabelecida é, ainda, centrada no indivíduo e a família é vista como unidade divisível em partes. **Descritores:** Autocuidado; Hospitalização; Cuidador; Família; Enfermagem.

RESUMEN

Objetivo: comprender el inicio del proceso de adaptación familiar a la situación de enfermedad con dependencia en el autocuidado en internación hospitalaria. **Método:** estudio exploratorio-descriptivo, de abordaje cualitativo, con acercamiento a la fenomenología. Datos generados a partir de entrevista semiestructurada en tres momentos. Los participantes fueron agrupados intencionalmente a partir del genograma, considerando el número total de cuidadores familiares que se convirtieron en dependientes, internados en el servicio de medicina de un hospital del norte de Portugal. **Resultados:** la situación en cuestión es experimentada por los cuidadores familiares con sentimientos de miedo e impotencia, generando esto múltiples cambios significativos en su vida personal, laboral y social; con repercusiones en el funcionamiento familiar. **Conclusión:** en el proceso del cuidar, la relación establecida está, aún, enfocada en el individuo, y la familia es vista como una unidad divisible en partes. **Descriptores:** Autocuidado; Hospitalización; Cuidadores; Familia; Enfermería.

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INTRODUCTION

Aging with prevalence of chronic diseases and consequent dependency on self-care has aggravated in the last decades, becoming one of the main health care concerns of the society, due to the significant impact on the financial and social system. In Portugal, the older population (over 65 years of age) represents today around 19.2% of the total population. According to current estimates, in 2050, this segment will represent 32% of the country's population.¹

As a health facility that provides different professional care, hospitals are often the only option to this population. However, the current emphasis on low-cost services leads to early discharges, returning patients to their homes, and transferring disabling patients to their families, who are forced to take care of their ill members, often without economic and housing conditions or proper knowledge.²

Assuming the role of a caregiver is a commitment that can be hard, not only for what this role requires, but also for the impact of this situation on the caregiver, constituting a great personal and family challenge, because deficiency, inability and disadvantage affect not only the patient, but also the family members, who are forced to develop strategies for an effective adaptation to health care challenges.³

In this context, the role of nurses is of significant importance, as they support and help such families find balance, allowing them to overcome the changes and favoring a faster and more consistent adaptation process. However, during our professional practice, we see that, although nurses acknowledge the importance of families, their actions often indicate failure to be involved in caregiving and supporting these families, and this situation justify the development of this study, focused on the experience of families in the early stage of their patients' dependency, with possible new contributions, despite being a complex path.

This study was developed on the basis of a central question: Do families develop specific strategies during hospitalization to help their dependent patients? To answer this question, the early process of family adaptation to a disabling disease in self-care was analyzed during hospitalization.

LITERATURE REVIEW

The early phase of a disease is a situation with changes in the family functioning. It corresponds to a moment of crisis in the life of patients and their family; a transition is

seen,⁴ requiring adaptation to the new condition and changes in several aspects of the daily life, which assume a permanent character for dependency in terms of self-care. Moments like that generate great stress, as the crisis is felt by everyone as a threat, due to the unpredictability of the facts,³ affecting the balance of a family, once changes are in a short time, demanding special skills for a proper answer.

The transition of older people to dependency in self-care has immediate effects of family readaptation, as patients are no longer able to fulfill their needs alone. Dependency refers to a person's inability to adopt proper behaviors or perform actions to reach an acceptable level of satisfaction of their needs, and its diagnosis is of great relevance in the nursing practice.⁵

When handling dependency, the family remains the main source of direct care, psychological support and social contact. With several changes along time, the concept of family has changed, but it could be defined as a group of people connected by consanguinity, affinity, emotional or legal relationships, and such unit or unity considered as a system that is greater than the sum of its parts;⁶ somehow, family is more than consanguinity or co-residence, with particular reference to its psychological and sociological dimensions.⁷

In the contemporaneous society, the needs and expectations of families are different,⁸ but seeing the family as a whole, as a unique and particular "being" is more important than having a focus on a stable construct, understanding the theme analyzed in this study involving. Thus, family is understood as a system, a whole, a globality that can be understood only in this holistic perspective.⁹

This systemic view makes each family different from one another, with unique lifestyles, as no matter the family model, it is always a group of people who establish relationships with the outer environment. As a family is a dynamic system of continuous and interconnected relationships, any alteration will affect both the parts and the whole, and both tend to promote the change for the dynamic balance of the family.⁷ That interdependency contributes to a family's ability to adapt and keep homeostasis.⁷⁻¹⁰

The presence of a dependent person directly or indirectly changes the nature and dynamics of family interactions.⁹⁻¹⁰ The family becomes unorganized, responsibilities and roles previously assumed by the patient are delegated to other members or are not fulfilled due to unawareness or lack of consensus, resulting in a conflict of roles, a

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frequent situation for the person who assumes the role of a caregiver.

The progressive requirements related to informal care and the potential repercussion in different levels make families see this situation as a problem,¹¹ as providing care to a dependent person affects many aspects of the personal, family and work life.^{3,12} However, little attention has been dedicated to changes in the development conditions of patients with disabilities and their families, or to the psychosocial effects the problems of disabilities cause to dependent patients and their family.³

In nursing practice, family intervention is often seen as a resort. Family is still seen in a fragmented way, a group that can be broken into parts, in which nursing care is focused on the patient, without considering their family context.⁷⁻¹⁰

Families may be more or less capable to deal with the crisis caused by the disease of any of their members, but it should be noted that the adaptive answer to the disease depends, to a large extent, on how the disease is accepted and experienced, already during hospitalization, and the relationship configuration of family cohesion before the disease.¹³

Families guide the actions,¹⁰ and nurses have the role to promote the health of family members and the family system, meeting their needs as a whole, which requires collaboration among professionals and the family, as it allows sharing and reciprocity in collectively understanding the disease.¹³ Therefore, it is extremely important that nurses think about caregiving families, paying attention to how they handle the situation, from hospital admission to discharge, so that they can together develop coping strategies.

METHODOLOGY

This is a qualitative descriptive exploratory study, based on a phenomenological design, as it is considered the most adequate method for the objectives and subjectivity of the theme.

The participants were six family caregivers of patients hospitalized in a medical service of Porto, northern Portugal, respecting the following criteria: relatives of patients hospitalized due to an occurrence that generated dependency; relatives who decided to accompany the patient during hospitalization; relatives who lived with, or started living with, the patient; relatives who would aid the patient at home after hospital discharge.

Data were collected by means of semi-structured interviews conducted at three

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distinct times: the first at admission, the second one week after admission, and the third at hospital discharge. In total, 18 interviews were conducted, three with each caregiver. The questions from the first interview aimed to learn about the experiences of caregivers related to the dependent patient's needs. The questions from the second interview aimed to learn about the experiences of caregivers related to the caregiving process during hospitalization. In the third interview, the questions aimed to learn about the experiences of caregivers related to returning home, the time of facing reality.

All ethical aspects were respected, from problem identification to study conclusion. The participants agreed with the study by signing an informed consent form. Each interview lasted about 45 minutes, with small differences according to each case. The project was approved by the Institution's Ethics Committee, protocol 3756, on November 3, 2005.

Data were analyzed by means of Bardin's content analysis method,¹⁴ with the aim to contextualize and understand the experiences of caregiving in dependent patient self-care impacting the family, in the perspective of each family caregiver.

RESULTS AND DISCUSSION

Among the six family caregivers interviewed for this study, five were female, married and daughters, followed by one daughter-in-law, and only one male participant, a nephew. Their ages varied from 40 to 67 years, mean age was 50 years, most were married. These results were similar to those found in other studies that analyzed caregivers of old-age patients.^{12,15} In terms of educational attainment, completed primary school was predominant. Of all six caregivers, four were retired and two were at working age, one of them in a part-time job. They were predominantly from the rural area, only one from the urban area; all family caregivers lived in the same place as their related dependent patients, and they were from families comprising three generations, of low socio-economic level, corresponding to relative poverty and, particularly, extreme or critical poverty. Each analyzed family presented particularities regarding their way to provide care, understand the disabling disease, and express their feelings at each moment. Then, based on the speech of all six participants and to achieve the proposed goals, data were categorized by themes, highlighted in Figure 1, for result analysis.

Category	Subcategory
1st moment - Hospital admission	
A. Caregiver's feelings	- Negative feelings - Positive feelings
2nd moment - One week after admission	
B. Challenges related to providing care to a dependent person	- Fulfilling the needs of dependent person/performing the role of a caregiver - Physical challenges
C. Needs perceived by the caregiver	- Need for training - Need for help - Need for the development of coping strategies
3rd moment - Hospital discharge	
D. Caregiver's perceptions about nursing support	- Moment of discharge planning - Family-centered care
E. Implications of dependency on the family and caregiver's life	- Social and family restrictions - Caregiver role burdens

Figure 1. Speech categorization

At the **1st moment**, the situation of dependency of a family member causes ambiguous feelings in family caregivers, but the negative feelings are one of the most important and strongest sensations experienced in this early period. Caregivers attribute these feelings especially to the lack of support from health professionals.¹⁶

♦ **Caregiver's feelings upon dependency**

Insecurity - Doubts about their ability to provide care at home generate feelings of insecurity in caregivers, especially when they realize the family member's health condition will not change:

At this point, only physicians can treat her, right? [...] no one knows what to do. (E4)
While he is hospitalized, [...] it's safer; then, at home, I'm afraid that he won't breathe, because, as he was paralyzed, I'm afraid, expectoration matter may build up [...]. If I need oxygen suddenly, [...]. (E3).

It should always be considered that families are not prepared to assume the responsibility and dependency of a family member, and the challenges of performing tasks generates insecurity and feelings of incapability,¹⁵ once caregivers also perceive a risk to the patient.¹⁷ Similar perceptions were reported by other authors, who highlighted that lack of support from relatives overwhelmed caregivers already during hospitalization, a factor that may exacerbate this feeling.¹⁷⁻¹⁸

Suffering - Suffering of caregivers is a result of the patient's loss independency, the nature of care needs and changes in the personal life and family relations due to this situation:

Now we spend almost all the time around him. It's different. (E5).
[...] I'll bear my cross [...] Suddenly [...] I get afflicted, I'm very afflicted, very nervous [...]. If I see a sick person, I get sick too. (E3)

As an inner and personal experience, suffering is variable, and for this reason, it is subjective and not very explicit; then, in this context, every family faces dependency in its own perspective, focused on its values, beliefs

and perceptions, which should be captured by nurses, in a holistic and appropriate understanding of its caregiving possibilities and potentialities, as already reported by other authors.¹⁹⁻²²

Feeling of powerlessness - The feeling of powerlessness experienced by caregivers and generated by dependency comes from an absolutely unexpected and unknown context, it may result from any unpredictable situation.

[...] What will I think of that? (E3). It's a case I didn't count on for now, I didn't count on this situation, but it came, and as it is the reality, I'm afraid of it, I fear it [...]. I don't know if I'll be able to handle it [...]. (E1)

It happens especially when there is no prior training,¹² which agrees with data from other studies, as half the number of caregivers were experiencing this situation for the first time. This aspect may upset the balance of a family, due to its somewhat anxiogenic impact and the resulting changes, leading them to an accidental crisis of some level of complexity.³ The contact with a strange hospital greatly contributes to that, combined with the family's frailty and the lack of explanations from health professionals.¹⁸

Hope - Despite everything, a disease may bring positive feelings and aspects to a family, making it stronger;³ some caregivers report they hope the patient's clinical situation improves, the patient is healed from the disease and recovers dependency, reducing suffering and generating comfort in the stressing situation they experience:

[...] time will show what he needs. (E4)
The doctor believes he will recover, as he is still young, [...]. (E6)

For the relatives, it is difficult to accept patients are dependent and requiring continuous support; they also fear what is for sure: the presence of a disease and dependency until death.¹⁹ Then, the adaptation of family caregivers to this difficult situation is impacted by several

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factors, and it is easy to understand that, in the presence of insecurity, fear and suffering, excitement about life and hope for better days are important aids to face crisis.

At the 2nd moment, after an active participation in the provision of care, family caregivers face difficulties resulting from caregiving, which agrees with the results from other studies,^{11,14,17} but disagrees with the reality reported by a study on family members of cerebrovascular accident patients, in which 67.8% did not find any challenges.³ Likewise, they feel there are challenges to overcome, using coping strategies.

Challenges associated with caregiving - When fulfilling the needs of dependent people/performing the role of a caregiver.

All analyzed patients presented full dependency when performing activities of daily living, resulting from a cerebrovascular accident, a cardiovascular pathology, and most caregivers referred to it as the most difficult challenge to fulfill their needs, even those who had already been caregivers, with fear to fail and respond appropriately:

[...] because we don't know how to handle this situation, it's like a baby, but much larger and heavier, [...]. [...] I thought I wouldn't be able to see her with the tube, eating through the tube, all these things, I thought I wouldn't be able, for me, I was not able, [...]. (E2)

In the first phase, it's complicated, because I used to see my mother independent every day [...]. (E4)

The caregiving task may become scaring and cause affliction, particularly when caregivers do not see the possibility to share the task with other family members. They often feel guilty and in debt, because of the patient's suffering or for not being able to properly handle the situation as they would like to.¹⁹⁻²¹

Physical challenges - It should be noted that our study, despite presenting mean age of caregivers of approximately 50 years, shows a high number of people retired due to the disease, which does not agree with other studies in which most caregivers are old-age people.² It seems to be unanimous, as participants feel physical effects related to their efforts, becoming exposed to serious health risks.

I'm afraid I can't be [...] I'm afraid he goes down and I can't [...]. (E2)

[...] I'll have to do it this way, my best [...]. (E3)

[...] these are things I can't do alone [...]. (E4)

For some authors, feeling tired and presenting worsened health conditions due to

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frequent caregiving may affect the role of a caregiver and their personal life, leaving their own needs aside and underestimating their own health problems.^{2,11}

Needs perceived by caregivers related to caregiving at home

To provide the necessary aid, caregivers reported they feel they need training and support from other people. Other studies presented similar data¹⁹, showing caregivers' needs related to essential actions and strategies to promote the patient's comfort.

Need for training - The need to learn new skills appears to fulfill the dependent person's needs, allowing caregivers to handle caregiving tasks:

[...] we learn to do things over time. (E1)

[...] there's a lot to learn [...]. (E4)

In this context, they need to be trained to acquire practical knowledge about how to take care of the patient's personal hygiene, put the patient to bed, move the patient from bed to a chair and vice versa, and feed them:

In personal hygiene, turning him, sitting him, [...]. When feeding him (E6).

Data from a study conducted in Sweden shows high evidence that caregivers who live with old-age people wish to fulfill their training needs.¹⁷

Need for help - After providing care, caregivers became aware of the physical effort and reported their need for help to other people in caregiving, sharing the task with other family members, thus minimizing the negative effects of caregiving:

[...] ask somebody to help. (E1)

[...] the important thing is that they (family members) help, [...]. I was not able alone. (E5)

I can't do it alone, God forbid, [...]. I get help from them [...] from the hospital [...]. (E6)

Results in agreement with those from other studies^{2,11} show the need for help from other people, although some studies conducted in Taiwan and the United States consider the caregivers' needs change over time during the caregiving period, with different needs in distinct phases of the adaptation process, in the transition from hospital to home.¹⁷ In this case, we could say health professionals in charge of planning hospital discharge should identify post-discharge needs, as early as possible and prepare the caregiver and the family, as these needs are different from those during the hospitalization period.

Need for development of coping strategies - Considering post-discharge challenges are predicted, we asked caregivers about the strategies they use to handle such challenges and ensure protection to the

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patient. The strategies reported by them were sorted in two categories: strategies for problem resolution, when they aim to resolve the problem, and strategies based on the management of emotions, when they aim to adjust or relieve the affective status associated with stress, even if the problem remains unsolved.²¹

Acceptance of new situation - One of the strategies involved awareness of the change and involvement in the caregiving process, addressing the requirements of caregiving tasks and the changes resulting from such situation:

We left all behind, we have to look ahead. (E5)

But it's an adaptation that should be made [...]. (E4)

This positive perspective of facing the situation was the solution found by caregivers to make their caregiving easier, during the transition they are having in their health/disease status, which is directly related to their quality of life and a determinant for family adaptation. Such data are similar to those reported by other studies.¹¹

Dedication to work - The caregiver's work dedication to keep busy and temporarily forget about the situation was reported by caregivers as a source of support:

What also made me feel good [...] was the fact that I didn't leave my job; I'm a clerk and I talk to many people, I speak, I laugh, [...]. (E1)

In this speech, the interviewee indicates an out-of-home job is good for the caregiver's life, although it does not solve the problem, but it eases the discomfort that supposedly cannot be changed. However, some authors disagree with this idea, reporting serious repercussion from the dilemma working caregivers face on whether they should go to work or take care of the ill family member.¹² In our study, it seems to be positive, as this caregiver shared the caregiving tasks with another family member, who lived with the dependent patient.

Help from supporting groups - Help from supporting groups as providers of formal and informal care, was especially seen in family members who lived with the dependent person and in the institutional home support service, to fulfill the needs of the dependent person, particularly for the provision of hygiene care and comfort and for household support services, followed by the acquisition of technical aids, especially the articulated bed:

Her husband also helps and the girls too, it's easier for me. (E2)

An association here in Mindelo, which takes care of the clothes, feeds, cleans my mother's bed [...] and takes care of her, gives her a bath [...]. (E4)

We got an articulated bed. (E5)

This type of support was also identified in other studies as the most frequent help to caregivers in their caregiving tasks are performed at home.¹⁵⁻¹⁶

At the **3rd moment**, we wanted family caregivers to express their perceptions of the nursing support received during hospitalization and the impact of dependency on the personal and family life when returning home, minutes before the discharge.

◆ Family caregivers' perception of nursing support

Moment of discharge planning - The interviewees reported nursing professionals provided instructions near the discharge.

[...] she stayed there during the last week. (E2)

Yesterday [...] (the day before the discharge). (E3)

Other studies confirm these data, suggesting caregiving instructions are provided near the discharge.^{18-19,22} However, differing data suggest that it is appropriate to start discharge planning as early as possible, so that the family member will plan their time and availability to adapt to the new role of caregiver, gradually acquiring the required skills.⁵ Besides, "[...] a short time after the accidental crisis starts, the shock and stress [related to the role to be performed] are still very strong:³

At the end of the second day, they wanted me to come and learn how to give her a bath and clean her, [saying] that I'll have to take care of her, because at the end of this week, when she had the paralysis, she had to go home. That was a bucket of water, it's not normal, it's ice, because this situation is complicated for me, because I've never been through such a thing, and at the end of the week, they told me she was already going home, it's very complicated. (E4)

Studies explain the reaction of caregivers, after the disease impact, the denial of the situation and disorganization of family balance, experiencing their own family, during the disease trajectory, a number of situations to be adapted to.² Another important aspect to be considered is hospitalization, which may be disturbing to the family, as it shows an unknown, scary reality, full of uncertainties, in which a family member is inserted,¹⁸ because, caught in the web of an accidental crisis, it requires some time and some help to resolve the situation and effectively support the patient.²⁻³

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Family-centered care - Knowing the disease requires continuous attention after discharge, during hospitalization, the family⁷⁻⁹ assumes the commitment to provide care, and for this reason, they should be trained, supported and encouraged by health professionals. However, in practice, we see family-centered care in hospitals is still deficient, as it remains centered on the needs of the dependent patient.

The nurse told me to learn how to wash her and take care of her [...]. (E2)

In hygiene, when turning him, sitting him, [...] although I didn't fix many things in my mind. (E6)

[...] I have to wash him [...] feed him via tube [...]. They taught me how to turn him this way and that way and how to get up [...]. (E3)

This result agrees with that from another study conducted at the same hospital: the diagnoses identified by the nurses are mostly associated with the intervention functions focused on the individual (59.1%), accounting for only 0.7% in the family.⁸ This way, health education provided by nurses to caregivers about differentiated care is essentially focused on instrumental care, more focused on self-care,¹⁶ and the family is seen as a resort in nursing care.

In practice, nursing actions are not provided to the family, but to caregivers only, and related to the caregiving task, as that was the case for the prevention of complications: the caregiver was seen as the caregiving person.

[...] the nurse [...] because the hospital bed is very high [...] very different from the bed we have at home [...] which are low and [...] we don't need to bend or force our back [...] lift weight and make movements with our back and knees and that might help me [...]. (E4)

The reports of participants suggest a concern about having some training, which would insert them in the nursing care plan and show an attitude of partnership with the caregiver in the caregiving process, certainly promoted by the work methodology adopted by the hospital of the reference nurse model. Knowing the engagement of both the patient and family in the caregiving process has a positive impact on the caregiver's well-being; health professionals are advised to adopt some behaviors to promote it.¹³

All interviews clearly showed the family was excluded from the attention as a client:

During the hospitalization period, nobody said anything about the attention I should have [...]. About the family, I have no idea. (E5); No, nobody said anything. Not even about the family, never. (E3)

Similar results obtained in a hospital

concluded nurses provide care to the dependent individual only, forgetting about the main caregiver and the family.¹⁶ In fact, this situation indicates that providing attention to the family is not very explicit in the practice of nurses, showing the challenges to be handled during the caregiving process.

Impact of dependency on the life of caregiver and family - The impact of caregiving on the life of the caregiver and the family is known. When the caregiver dedicates much time to dependent patients, they have no time to themselves, leading to an unbalanced family.³

Social and family restrictions - Reduced social and family activity becomes frequent to people assuming the role of a caregiver, as suggested by the participants:

That's how it works: when I want to go out, my father stays with her; when my father goes out, I stay; she's never alone [...]. (E1)

We used to go on excursions [...] never more; I used to go out and come back late, but now I can't do that; [...] I was always with a friend or I used to go to the morning mass [...]; now, it's going to be different, I know. (E3)

A direct impact is observed on the caregivers' life, as indicated by the interviewee (E1) reporting a sensation of having lost her autonomy in her own life, living exclusively for her ill mother. Another caregiver (E3), as she lost her partner for trips and tours, predicts that she will never do that again. Limited free time for leisure activities and for the family are results also found in other studies,^{11,17,22} leading the caregiver to social isolation already during hospitalization, due to the extended time in the hospital.¹⁸ However, other investigations show positive changes, like stronger family relations.^{12-13,23}

Caregiver role burdens - Burden is the term mostly used in the gerontological literature to describe the negative effects of caregiving on the caregiver^{21,24-25}. The burden on our participants was mostly related to physical and psychological aspects:

I'll have to take care of him. [...], Now, everything is on me. (E3)

Yes, I knew it would be a big trouble [...]. (E5)

[...] it's a concern [...] I have a person to take care. I'm sincere, it's a big responsibility. (E6)

These results agree with those from other studies on this theme, showing the responsibility assigned to the caregiver is due to the complex care to be provided on a daily basis,^{22,25-26} interviewee E3 reports lack of support to share the caregiving tasks and perform other functions. Several studies have shown the physical burden associated with

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multiple roles generates changes in family functioning and dynamics, with a negative impact on family economy, health and quality of life of family members^{13,15,24-25,27}. Unlike the findings of other studies showing changes in professional dynamics reported by the participants, nobody reported such changes in our study.

CONCLUSION

The experiences of family caregivers in cases of dependency of one of their family members show the results of this study: the family adaptation process to a disabling disease situation takes place in many ways, from start to end of the hospitalization period. The family goes through different phases, involving different needs for support aiming to reach family balance. The interviews with the participants at three different times showed the differences are related to the transition periods every family goes through, according to each family's background and perception.

1- At *admission*, the negative feelings represent the strongest sensations they feel. They are focused on the patient's health status and are not very receptive to discharge instructions, which indicates the need to understand family interactions with the disease to perceive the family as one of the focus of nursing care.

2- During the *hospitalization* period, they prioritize the patient's needs over theirs, showing self-care *challenges*, developing *coping strategies* aiming to have an effective adaptation to health challenges. In this phase, nurses should act more proactively in relation to the family needs, to guarantee the supporting role to the patient, as the type of approach to such family needs will certainly affect the strategies used by them to overcome difficult situations.

3- At *discharge*, they have significant changes in their personal life with an impact on the family as a whole, due to the patient's needs, such as loss of freedom and multiple roles assumed by only one caregiver.

In terms of nursing support, the results show care provision is focused on the dependent patient, especially when preparing the caregiver to perform the caregiving task. This fact allows to conclude that it is still difficult to address the family as a client.

Different practices are adopted by the health team, indicating that there is no conceptual model adjusted to the contexts, which are crucial to understand the family system as a unit of care provision, as suggested by other studies. Therefore, it is

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extremely important to understand this problem and help make it evident in nursing practices.

Understanding family background in the dependency process in a hospital is extremely important to allow nursing, as a discipline, to restructure its professional practices, especially focusing on the family core, and not only on the patient and caregiver, developing adjusted interventions and providing an effective monitoring to families, to honor the profession and promote nursing care to families.

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