http://www.periodicos.uem.br/ojs/index.php/CiencCuidSaude
ISSN on-line1984-7513
DOI: 10.4025/ciencuidsaude.v21i0.61823

ORIGINAL ARTICLE

INFORMAL CAREGIVERS' EXPERIENCE IN ROLE TRANSITION AFTER DEHOSPITALIZATION

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ABSTRACT

Objective: to understand the experiences of informal caregivers of dependent people in the role transition process after dehospitalization. **Method:** a descriptive, exploratory, qualitative study carried out with informal caregivers of dependent people who participated in a protocol of instrumentation for discharge. Data collection took place with 10 participants from southern Brazil, between July and August 2021, through interviews conducted at home. For data organization, we used IRAMUTEQ®. Analysis was anchored in the Transition Theory. **Results:** the results addressed the process of situational transition of informal caregivers, emerging three final classes: Class 1 - Difficulties in the daily care of dependent people; Class 2 – Meanings given to role transitions; and Class 3 – (Dis)continuity of care after hospital discharge. **Final considerations:** it was possible to understand that the experiences were permeated by inhibiting factors so that the meanings given to this experience were associated with the difficulties with the transition to the role of caregiver. Nurses played the role of facilitator in the situational transition process, by accompanying them, guiding them and enabling them to develop new skills.

Keywords: Caregivers. Patient Discharge. Transitional Care. Nursing Care.

INTRODUCTION

Informal caregivers are defined as the person who provides care to other dependent people, often without receiving financial remuneration and without having professional training to perform it. In the event of a person's illness and incapacities that result in dependence, one of the family members usually take the responsibility and the role of caregiver. It is considered that 80% of the total hours of care are performed by these family members or people who provide informal care(1).

Becoming a caregiver is a demanding role, whose responsibilities range from assistance in activities of daily living, medication management, health care coordination, in addition to self-care itself, which can extend over a long period, which can negatively impact their well-being and health(2). When confronted with the new reality, informal caregivers often do not feel prepared to assist their family member, which results in frustrations, fear and a feeling of loss of control over one's own life, facilitating the development of depression and/or anxiety(2). The literature demonstrates that caregivers assist their family members without adequate guidance and, for the most part, are alone in care task(3).

In this context, the transition process in becoming a caregiver implies learning to play a new role, in which different activities will be part of their daily lives. Therefore, it is necessary for the health team to prepare them to develop

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the required skills, actively involving them in the planning of care for discharge, with a focus on role transitions, in order to promote continuity of care(4).

Transitions are the central phenomenon in Meleis' Transition Theory that describes and supports the relationship between patients and nurses whenever health constitutes a process of change; in this sense, the problems experienced by people are points of intervention by nurses. Through this theory, it is possible to understand human experiences and reactions as a result of these periods of change, helping nurses and the health team to identify facilitators and inhibitors of transition conditions and in the implementation of actions for the passage from one state to another safely(5).

However, occasionally, health professionals do not address the required skills and changes in an individual's life when they become a caregiver during hospitalization, which leads to fragmentation and discontinuity of care(6). Although preparation for discharge is important, a quasi-experimental pilot study conducted with families of dependent people identified that guidance provided only during hospitalization was not enough to guarantee caregivers' competence at home. The need to follow up families after discharge was evidenced, in order to identify their demands to instrumentalize them in this transition to reduce stress and insecurities(7).

Returning from the hospital to home with a dependent person exposes the family and the dependent to harm, leading to problematic or prolonged recovery and mental illness. Therefore, it is necessary to employ Meleis' Transition Theory, which enables the understanding of a complex and vitally important period, such as the transition from the role of family member to caregiver (situational transition) in the dehospitalization process, whose experiences have repercussions not only on the sick person, but on their families(5).

Thus, paying attention to the experiences of families caring for a dependent person after hospital return is important, because understanding how new routines are established and how old ones are restructured after this event that generates transformations can allow the elaboration of real, sensitive and holistic interventions for users, their informal caregivers and their families' demands(6).

In this perspective, this study was developed from the following question: what were the experiences of informal caregivers of dependent people in the role transition process after returning home from the hospital? Therefore, the objective was to understand the experiences of informal caregivers of dependent people in the role transition process after dehospitalization.

METHODOLOGY

This is a descriptive, exploratory and qualitative study, anchored in Afaf Meleis' Transition Theory(5), which analyzed the situational transitions experienced by informal caregivers of dependent people who participated in a protocol for discharge when returning home. It is noteworthy that this work was prepared based on COnsolidated criteria for REporting Qualitative research (COREQ) and is part of an umbrella project called "*Plano de alta para pessoas dependentes de cuidado e seus cuidadores informais*", covered by CP 11/ 2020 - Research Program for SUS: Shared Health Management - PPSUS Edition 2020/2021 - 11/2020, funded by the *Fundação Araucária* (Araucária Foundation), developed by a state university in southern Brazil.

Only informal caregivers who completed the educational intervention proposed by the umbrella project participated in the study. They were followed at home for 30 days after hospital discharge. The protocol included the identification of real needs and available resources, verbal guidance, care technique training, coping strategy and caregivers' self-care(7).

We selected participants aged 18 years and over, indicated as the main informal caregivers of people classified with total to severe dependence, which corresponds to the global score in the Barthel index between 10 and 30(8) and who were admitted to one of the two public hospitals in the municipality where the study was conducted (in the medical clinic, surgical clinic and COVID-19 clinic sectors). It should be noted that these institutions were selected because they have similar characteristics among the public served (adults/elderly with significant dependence and socioeconomic fragility) and lack of established routine of hospital discharge, without intending to change the municipality and keep the telephone contact updated during the conduction of the study. We excluded caregivers whose dependent person died after the end of the educational intervention protocol or who did not respond to telephone contacts after three attempts on alternate days.

Among the 37 eligible informal caregivers, 17 were excluded due to the death of the dependent person; seven were not found through telephone contact and/or moved to other cities; and three refused to participate for fear of receiving the researchers at home and favoring the contamination of the dependent family member due to COVID-19. Thus, 10 informal caregivers participated in this study.

Data were collected from July to August 2013. The study population was previously contacted by telephone to schedule the best time to meet and submitted to a semi-structured interview that was conducted in participants' homes. The interviews took place only once with each participant and started with the following triggering question: how was your experience in participating in an educational intervention to plan the hospital discharge of your family member to return home? Other questions of narrative aid were used in order to enrich the interview. The speeches were recorded in digital media, transcribed in full, and the language vices were corrected, without changing their content, just to give fluidity to the reading. After transcribing the material, the audio files were destroyed from all media.

At the end of the interviews, a synthesis of the content discussed with participants was elaborated, in order to reiterate the information and correct erroneous interpretations. Field notes were performed immediately after contact with participants.

The interviews were conducted by two nurses, with a PhD in progress and experience in this area of knowledge, and a nurse, a technical fellow in the larger project. It is worth mentioning that all safety guidelines to avoid transmission by COVID-19 were strictly followed, contemplating the distance between people, use of mask and airy environment.

The COPER 14 instrument was applied to characterize the population, which allows assessing informal caregivers' cognitive, psychomotor, emotional and relational competence, with a Cronbach's alpha of 0.82(9). It consists of 14 items, whose results are grouped into quartiles, receiving the following classification: up to 17, low competence, 18-35, low competence, 36-52, good competence and >53, excellent competence(9). The following variables were used from the instrument: caregiver - gender, age (years), education (years of study), monthly income (minimum wage in force in the country in 2021), experience as a caregiver and COPER score; dependent person - age and degree of dependence.

As a methodological framework, thematic content analysis was used, which aims to unravel critically through inferences that seek to clarify the causes of a problem or the possible consequences arising from it. We followed the three proposed phases: pre-analysis; material exploration; and treatment of results(10).

To help organize and present data, we used the *Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires* (IRAMUTEQ®) 0.7 ALFA 2.3.3.1. The Descending Hierarchical Classification (DHC) was adopted, in which, from a textual corpus, constructed with fragments of participants' speeches, it is divided into text segments or Elementary Context Units (ECU), which are classified according to their respective words, and distributed according to their frequency(11). In order to build the definitive classes and their nomination, the main issues and their convergence with Afaf Meleis' Transition Theory theoretical framework that permeates this work were considered.

The study followed in accordance with Resolutions 466/2012 and 510/2016 of the Brazilian National Health Council. The study was approved by the Research Ethics Committee of the *Universidade Estadual de Maringá* (Opinion 2.180.586). All participants signed the Informed Consent Form (ICF) in two copies of equal content. In order to preserve participants' identities, the following identification was adopted: Participant n, age (e.g., Participant 1, 45 years old).

RESULTS

All participants were female, eight daughters, one granddaughter and one wife. Age age ranged from 22 to 59 years (average 45 years), with four to 13 years of education (average nine years) and an average monthly family income of US$284.08. Four participants described being the only caregivers, not receiving support from other family members and none had previous experience with care. As for the competence to care, the participants' average score at the time of the interview was ±20.5 (low competence).

The textual corpus presented 286 text segments. Through the DHC, 236 were analyzed, which corresponds to a utilization of 83% of the total. The software indicated organization of the content in three initial classes, from the convergence with the adopted framework. The final classes emerged, namely: Class 1 - Difficulties in the daily care of a dependent person; Class 2 – Meanings given to role transitions; and Class 3 – (Dis)continuity of care after hospital discharge. Figure 1 demonstrates the process of organizing the segments and the design of the thematic classes that address informal caregivers' situational transition when they return from the hospital to home with a dependent person.

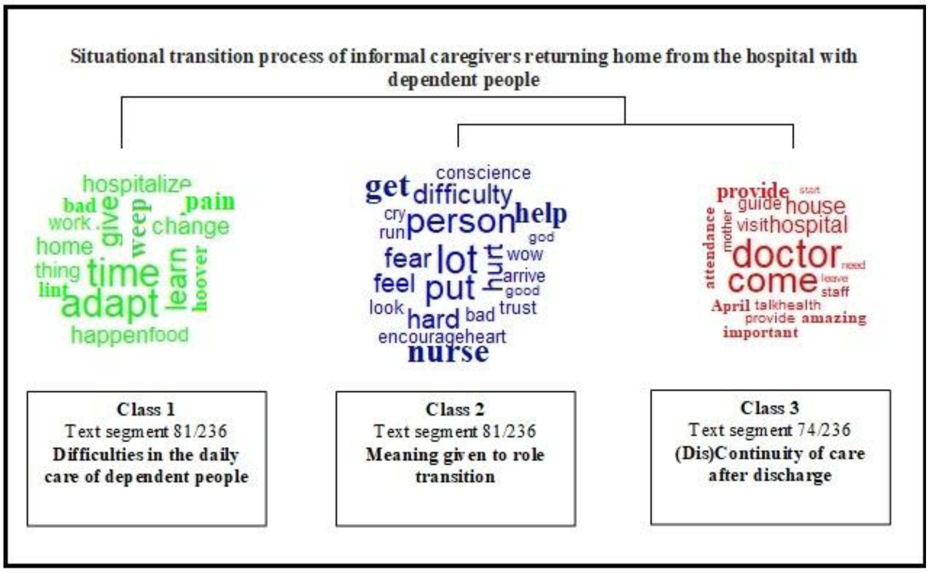

Figure 1. Class dendrogram, Paraná, Brazil, 2021

Class 1. Difficulties in the daily care of dependent people

This category represents the inhibitory factors that presented in daily life after returning home with a dependent person. Adversities emerged from the experience of the situational transition, transforming the role from family member to caregiver.

> [...] so, it's a total rush here, really rush. I don't have time to stop because if the helper wasn't here, I would have to prepare lunch and, during my lunch, I would have to stop to see if it's dripping (enteral diet) and if it's over I have to stop eating lunch, put water on, clean the tube. All this during my lunch [...] I don't like it, I really don't like it (aspirate the airways). I think it mistreats her (mother) too much, I'm often aspirating and she's crying. I don't like it, because I know how bad it is, I feel very nauseous [...] **(Participant 01, 45 years).**
>
> I was really concerned when my mom came home because I knew it would be me morning, noon and night. I was very insecure about what was happening. She (mother) had to be hospitalized because she didn't know what to do, what medicine to take. At home, it was difficult because I had to reconcile everything. But, because I needed to work from home, it became a situation of extreme discomfort because nothing was ever good about what I did for her **(Participant 08, 59 years)**.
>
> I cried when I heard that my mother was going home, I got despaired. I didn't know what to do, I already thought she would die in the transport home. The first week was turbulent because she

> did not adapt to the diet, she had reflux and had bronchoaspiration **(Participant 07, 35 years).**

> The biggest difficulty was when she choked (dependent mother). She choked on her own saliva, she was already using the probe, so she tried everything to get back and she couldn't, she tried, but she couldn't **(Participant 01, 45 years).**

> I was too afraid to mess with him (father). I was afraid of picking him up and hurting him, I kept thinking about how I would bathe him **(Participant 10, 59 years).**

The words that stood out the most in the speeches were suffering (n=16), crying (n=16), alone (n=12), aspirator (n=6), gauze (n=12), bath (n=6), bad (n=15), (dis)like (n=6) and difficulty (n=6). They reflected the difficulty of an informal caregiver to perform the complexity of procedures related to the care of a dependent person.

Class 2. Meanings given to role transition

This class demonstrates the meanings given to the transition from the caregiver role, which resulted from new experiences and tasks performed, mostly, without the support of other individuals in the social cycle.

> There are days I cry a lot because I looked at the situation and asked myself: how can people? Yesterday I was walking around talking, leaving [...] she (dependent mother) is too young! It was hard to accept it, it was very hard to accept **(Participant 01, 45 years).**

> It was scary (coming home), there were two discharges, scary! (I) wanted (the mother) to come back, but I still had that fear, all the care and concern about saturation. To me, that (discharge) looked like a monster! And when that cylinder (of oxygen) arrived, I thought "Oh my God…" **(Participant 04, 42 years).**

> What we needed most was the support of the family and we did not have [...] the fear was that he (boyfriend) would pull the gastrostomy, because it was very uncomfortable. We were very afraid of him bronchoaspirating or choking **(Participant 06, 23 years)**

Among the excerpts, the expression of fear in leaving the dependent family member alone, concern with all care demands, crying when complications developed at home stand out. The words "monster" and "scary" can, in part, demonstrate the perception of the whole situation.

Despite the new routine, participants pointed to nurses as an essential tool to help them in this new reality. The following words were evident: good (n=19), help (n=16), nurse (n=15), care (n=15) and learn (n=12). These pointed out that nursing care in this critical period contributes to coping with the situation, as they are guided, welcomed and their demands are valued.

> That nurse came here, took my leg (with deep vein thrombosis) and told me to be careful, not to let it hang. I asked, but after (the nurse) left, I thought, "Oh my God, I could have asked more." It was so nice, a person you trust. Also, because it encourages the person, asking, saying what you have to say. If there's something that hurts and I'm making it easier (not following the guidelines), (the nurse) says she can't make it easier, she calls the attention, but this attention calling is good (Participant 03, 42 years).

> When they said (health team) that I had to give insulin (mother), I was already shaking, so much so that after the nurse explained again how to apply insulin, I felt calmer. When (the nurse) talked about the signs to pay attention, this was essential for me. When my sister called and said (that her mother was feeling sick), at the time I already thought about what the nurse said and said: call SAMU! I already thought about embolism! So, I know that (follow-up and guidance) helped a lot to pay attention **(Participant 04, 42 years).**

> What made it easier (returning home) were the instructions that the nurse gave us. She informed where we could go, how to proceed in some cases. What happened was something we had never heard of. If we left the hospital without the guidelines, we would be lost, we wouldn't know what to do, it would be very complicated **(Participant 05, 55 years).**

It is evident that the presence of nurses makes the process facilitated by the support in meaningful education, which leads caregivers to have greater autonomy and assertive decision-making.

Class 3. (Dis)Continuity of care after hospital discharge

In this class, it was observed that participants felt unassisted by Primary Health Care professionals after returning home, precisely in a period of complexity and vulnerability for both caregivers and patients.

> I still had the opportunity that my cousin came to do physiotherapy, but if not, I was here waiting until today! The (FHS) doctor only came here once (after discharge), then he never came again. In these two months he came only once, I think he had to come more often. In this part, it is important to leave the hospital with this purpose in mind (referral), to come to the house, but there is not, there is no one to come (at home), it is difficult **(Participant 02, 22 years).**

> Look so far, you (research team) were the most frequent ones in the care of my mother, after she left the hospital. They haven't sent a doctor yet **(Participant 04, 42 years).**

> The municipality needed to provide physical therapy. We do the basics we learned in the hospital and we don't have the income to pay because only one person works from home. There are days that go by and we end up not doing physiotherapy, but it's because it tires us out, exhausts us **(Participant 07, 35 years).**

> I regret that the visits only took place after the fourth surgery. Maybe if it had happened earlier, I wouldn't have gone to the extreme. I did not know that there was a risk of breaking the stitches, I did not receive this guidance, the lack of knowledge harmed me **(Participant 08, 59 years).**

The words that emerged from this class were hospital (n=22), home (n=23), doctor (n=20), important (n=8) and follow-up (n=8). It arouses the participants' desire to be accompanied by the Family Health Strategy team of their assigned area to request exams, consultations and welcoming.

DISCUSSION

The results showed that the experiences of informal caregivers of dependent people after hospital discharge are complex. The need to reconcile household chores with family health care resulted in fear and concern. The accumulation of responsibilities can trigger an overload on caregivers, especially due to the physical and financial burden that is proportional to the level of independence of the people assisted(12).

In this study, informal caregivers assisted people classified as total to severe dependence, did not rely on the help of other family members to support them in daily tasks and did not have previous experience with care. These associated factors are inhibitors of the healthy transition process, which is influenced by the context in which they occur, the culture, the support offered by the support network and the meanings given to the lived experiences. Meleis proposes that the complexity of transition situations should be looked at from the point of view of the integration between patients, caregivers, health providers and the health system and, in this integration, nurses play a central role, promoting the continuous management of care(5).

The transitions experienced by people in processes of change are evident in this study in which participants are in moments of transition from one state to another triggered by health events. Meleis' theoretical framework argues that nursing therapy involves preparing informal caregivers for this situational transition, including education and teaching actions to supplement the ideal conditions for these changes(13).

In this context, nurses should advise informal caregivers, using teaching strategies and supervised practice to facilitate the transition process, promoting and encouraging better health outcomes, including reducing factors that can induce anxiety, improving the clinical condition of dependent people and reducing complications and readmissions(6).

As for the meanings, one can identify the emotional overload that caregivers experienced during the transition of roles after hospital discharge, demonstrated as a frightening experience. When confronted by new demands and current abilities to become caregivers, concern, fear and anxiety aroused. Similarly, a study developed in the United States of America (USA) detected a high burden related to the caregiver role performance, associated with depressive and anxiety symptoms and lower psychological well-being(14).

Despite the experience being challenging, participants highlighted the follow-up of nurses after hospital discharge as essential for acquiring the skills and abilities required for the new role. Professionals should guide/train people to deal with the new routine, helping them to acquire knowledge to perform important procedures and techniques for home care. It is important that nurses know how to transmit information to caregivers, adapting the approach to the level of knowledge, beliefs and culture of those involved and especially, using creativity so that there is significant learning(15).

It is important to note that hospital discharge protocols must address the concerns of those involved in transitions focusing on improving communication and understanding the reaction patterns that, for Meleis, are known as process indicators, namely: feeling connected; in interaction; locate oneself; to be situated; developing trust; and facing(13).

Moreover, to ensure the effectiveness and quality of home care, it is essential to follow up caregivers in the long term through home visits and telephone contacts(7). From this perspective, home care (HC) is a continuity strategy for transitional care, however a study identified that HC has challenges that impair HC, such as the construction of a care plan that is not part of users' life context, health professionals' (un)preparedness and difficulties in teamwork. Nevertheless, when considering the scope of HC in the Unified Health System (SUS - *Sistema Único de Saúde*), obstacles associated with socioeconomic inequality and regional health resources are still encountered, which require greater attention to ensure access and continuity of care (16,17).

Participants in this study experienced difficulties in role transitions when facing the post-discharge period(5)that were only minimized by the support of professional nurses who were involved in the research and, after its closure, remained unassisted. The lack related to the follow-up of health professionals after returning from the hospital was identified in participants' reports. This makes them vulnerable so health professionals must pay greater attention and care to these people, guiding them, educating them and supervising the care provided in order to promote well-being, especially for those who experience tension in the caregiver role(2,12,18-19).

The discussion about continuity of care arises, given the fragility of primary care in monitoring the cases described in this study. Difficulties in agreements and communication between health services are evident. This fact can stifle the continuous assessment and teaching processes that are necessary in these moments of situational transition. It emphasizes the importance of developing, among the counter-referral team, the culture and the foundation based on the understanding of Meleis' Transition Theory so that the team that will continue to recognize patterns of the nature of transitions and, also, their facilitators and inhibitors of these conditions. Thus, they can act in order to support formal caregivers' transition processes in their homes (15,19).

Among the limitations of the study, we highlight the fact that the COVID-19 pandemic has made it difficult to conduct face-to-face interviews, due to social distancing measures, as well as the fear of receiving researchers at their homes, which could favor the contamination of their families. At this point, it is noteworthy that the dependent people assisted by the participants of this study were considered vulnerable and susceptible to illness and death by COVID-19. The disease, allied to the instability of the clinical condition related to level of dependence (severe to total), culminated in facing a high mortality rate (46%), characterized as an exclusion criterion, which restricted access to possible participants.

FINAL CONSIDERATIONS

Based on the results of this study, it is possible to understand the experiences of informal caregivers of dependent people in the role transition process after dehospitalization. It was noted that the experiences were permeated by inhibiting factors, such as the accumulation of household and care tasks, inexperience and lack of support from both family members and health professionals. The tension in the role of caregiver was evidenced, given to difficulties with the transition process, characterized by participants as fear, concern and anxiety. The role of nurses as facilitators in the situational transition process was demonstrated, with bond building, guidance and training for the development of new skills and competencies required in this new phase. The results reinforce the need for monitoring informal caregivers and dependent people after hospital discharge, objectively focused on identifying transition processes and their inhibitors as well as the need to develop new studies for the development of strategies for continuous monitoring of competence and transitions experienced by caregivers. This work contributes to nursing knowledge in the sense of applying the profession's own theoretical assumptions, such as the transition process and nursing therapy, in the reality of people facing the dehospitalization process.

VIVÊNCIA DE CUIDADORES INFORMAIS NA TRANSIÇÃO DE PAPÉIS APÓS O PROCESSO DE DESOSPITALIZAÇÃO

RESUMO

Objetivo: apreender as vivências de cuidadores informais de pessoas dependentes no processo de transição de papéis após a desospitalização. **Método:** estudo descritivo, exploratório, qualitativo, realizado com cuidadores informais de pessoas dependentes que participaram de um protocolo de instrumentalização para alta. A coleta de dados ocorreu com 10 participantes da região sul do país, entre julho e agosto de 2021, por meio de entrevistas conduzidas no domicílio. Para a organização dos dados, utilizou-se o *software* IRAMUTEQ®. A análise se ancorou na Teoria das Transições. **Resultados:** os resultados abordaram o processo de transição situacional de cuidadores informais, emergindo três classes finais: Classe 1 - Dificuldades no cotidiano de cuidados com a pessoa dependente; Classe 2 – Significados atribuídos à transição de papéis; e Classe 3 – (Des)Continuidade do cuidado após a alta hospitalar. **Considerações finais:** pôde-se apreender que as vivências foram permeadas por fatores inibidores, de modo que os significados atribuídos a essa experiência se associaram às dificuldades com a transição para o papel de cuidador. O enfermeiro desempenhou papel de facilitador no processo de transição situacional, ao acompanhá-los, orientá-los e capacitá-los para o desenvolvimento de novas habilidades.

Palavras-chave: Cuidadores. Alta do Paciente. Cuidado Transicional. Cuidados de Enfermagem.

VIVENCIA DE CUIDADORES INFORMALES EN LA TRANSICIÓN DE ROLES DESPUÉS DEL PROCESO DE DESOSPITALIZACIÓN

RESUMEN

Objetivo: comprender las vivencias de cuidadores informales de personas dependientes en el proceso de transición de roles después de la *desospitalización*. **Método**: estudio descriptivo, exploratorio, cualitativo, realizado con cuidadores informales de personas dependientes que participaron de un protocolo de instrumentalización para el alta. La recolección de datos ocurrió con 10 participantes de la región sur del país, entre julio y agosto de 2021, por medio de entrevistas realizadas en el domicilio. Para la organización de los datos se utilizó el *software* IRAMUTEQ®. El análisis se basó en la Teoría de las Transiciones. **Resultados**: los resultados trataron el proceso de transición situacional de cuidadores informales, surgiendo tres clases finales: Clase 1 - Dificultades en el cotidiano de cuidados a la persona dependiente; Clase 2 - Significados atribuidos a la transición de roles; y Clase 3 - (Des)Continuidad del cuidado después del alta hospitalaria. **Consideraciones finales**: se pudo comprender que las vivencias están marcadas por factores inhibidores, de modo que los significados atribuidos a esa experiencia se asociaron a las dificultades con la transición para el rol de cuidador. El enfermero desempeñó un papel de facilitador en el proceso de transición situacional, al acompañarlos, orientarlos y capacitarlos para el desarrollo de nuevas habilidades.

Palabras clave: Cuidadores. Alta del Paciente. Cuidado Transicional. Cuidados de Enfermería.

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Data de recebimento: 24/01/2022
Data de aprovação: 13/10/2022

Financial support

Institutional Program for Scientific Initiation Scholarships - PIBIC/CNPq-FA-UEM; Coordination for the Improvement of Higher Education Personnel (CAPES - Coordenação de Aperfeiçoamento de Pessoal de Nível Superior), Social Demand grant, process number 001. It was also funded by CP 11/2020 - Research Program for SUS: Shared Management in Health (PPSUS - Programa Pesquisa para o SUS: Gestão Compartilhada em Saúde) Edition 2020/2021 - 11/2020, funded by Fundação Araucária.