REVISTA DE ENFERMAGEM REFERÊNCIA
homepage: https://rr.esenfc.pt/rr/
ISSNe: 2182.2883

RESEARCH ARTICLE (ORIGINAL)

Caregivers' perceptions of the requirements of their role: A qualitative study

Perceção do prestador de cuidados sobre os requisitos para a assunção do seu papel: estudo qualitativo

Percepción de los cuidadores sobre los requisitos para asumir su papel: Un estudio cualitativo

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Received: 15.06.23
Accepted: 13.11.23

Abstract

Background: Assuming the role of a caregiver involves meeting several demands. Understanding the caregiver's perspective can aid in this transition.
Objective: To identify caregivers' perceptions of the requirements for taking on this role.
Methodology: A descriptive exploratory study with a qualitative approach was conducted, using semi-structured interviews with a convenience sample of nine caregivers of dependent persons without previous experience. The data obtained was analyzed using MAXQDA software and followed Bardin's principles of content analysis. Ethical principles were adhered to, and the study was approved by the Ethics Committee (opinion OBS.SF.245-2021).
Results: The data analysis revealed three categories and their subcategories: Awareness; Skills, (Feeling capable of providing care after hospital discharge; Knowledge; Capabilities; Emotional self-control); and Resources.
Conclusion: The requirements identified in caregivers' perceptions can improve nurses' assessment of the conditions that facilitate the assumption of this role in the context studied. Future studies should focus on the perceptions of health professionals/clinicians regarding this phenomenon.

Keywords: caregivers; qualitative research; nursing care; continuity of patient care

Resumo

Enquadramento: A assunção do papel de prestador de cuidados (PC) pressupõe a necessidade de um conjunto de requisitos. Conhecer a perceção do PC poderá facilitar esta transição.
Objetivo: Conhecer a perceção do PC sobre os requisitos para a assunção do papel.
Metodologia: Estudo descritivo exploratório, de abordagem qualitativa, através de entrevistas semiestruturadas a uma amostra por conveniência de nove PC de pessoas dependentes, sem experiência prévia. A análise de conteúdo foi realizada com recurso ao *software* MAXQDA e seguiu os pressupostos de Bardin. Os princípios éticos foram cumpridos. Parecer favorável da comissão de ética OBS.SF.245-2021.
Resultados: Da análise de dados emergiram três categorias e respetivas subcategorias: Consciencialização; Competências (Sentir-se capacitado para cuidar no regresso a casa, Conhecimento, Capacidades e Autocontrolo emocional); e Recursos.
Conclusão: Os requisitos identificados na perceção do PC poderão melhorar a capacidade de avaliação dos enfermeiros relativamente às condições facilitadoras à assunção deste papel no contexto estudado. Estudos futuros devem incidir sobre a perceção de peritos/clínicos acerca deste fenómeno.

Palavras-chave: cuidadores; pesquisa qualitativa; cuidados de enfermagem; continuidade da assistência ao paciente

Resumen

Marco contextual: La asunción del papel de cuidador (PC) presupone la necesidad de una serie de requisitos. Conocer la percepción del PC puede facilitar esta transición.
Objetivo: Conocer la percepción que tiene el PC de los requisitos necesarios para asumir el cargo.
Metodología: Estudio exploratorio descriptivo, con enfoque cualitativo, en el que se usaron entrevistas semiestructuradas con una muestra de conveniencia de nueve PC de personas dependientes, sin experiencia previa. El análisis de contenido se llevó a cabo mediante el programa MAXQDA y siguió los supuestos de Bardin. Se cumplieron los principios éticos. Dictamen favorable del comité de ética OBS.SF.245-2021.
Resultados: Del análisis de los datos surgieron tres categorías y sus subcategorías: Conciencia; Competencias (Sentirse capacitado para cuidar al volver a casa, Conocimientos, Capacidades y Autocontrol emocional), y Recursos.
Conclusión: Los requisitos identificados en la percepción del PC podrían mejorar la capacidad de los enfermeros para evaluar las condiciones que facilitan la asunción de este papel en el contexto estudiado. Futuros estudios deberían centrarse en la percepción de los expertos/clínicos acerca de este fenómeno.

Palabras clave: cuidadores; investigación cualitativa; cuidados de enfermería; continuidad de la atención al paciente

How to cite this article: Santos, E. J., Lopes, M. B., Manata, J., Santos, D., Limão, R., & Nunes, M. C. (2023). Caregivers' perceptions of the requirements of their role: A qualitative study. *Revista de Enfermagem Referência*, *6*(3, Supl. 1), e31501. https://doi.org/10.12707/RVI23.74.31501

Introduction

The increase in life expectancy and advancements in health care have resulted in a decrease in mortality rates, leading to a growing population of older and more dependent adults and the consequent increase in the number of caregivers. Although caregiving can be personally fulfilling, it can also cause physical, psychological, and financial problems (Swartz & Collins, 2019).

Health teams, including nurses, family members, and the person in need of care, as well as the caregiver themselves, recognize the challenges of taking on this role. Caregivers are responsible for providing a substantial amount of care, sometimes all of it, to people who are dependent in self-care or have complex therapeutic regimens.

According to the International Council of Nursing (ICN, 2011), a 'caregiver' is an individual responsible for providing care to a person. Becoming a caregiver requires internalizing the expectations of healthcare institutions, health professionals, family members, and society regarding the appropriate or inappropriate actions defined for the role of caregiver. This internalization process is expressed through behaviors and values. According to Article 2 of Decree-Law No. 100/2019, dated September 6, an informal caregiver is an individual who provides care for a dependent person permanently (main caregiver) or regularly (non-main caregiver) without receiving payment for work or care provided. This role can be performed by a family caregiver.

The role of the caregiver has a significant impact on the person being cared for, the caregiver, and their family. Therefore, the main objective of our study is to examine caregivers' perceptions of the requirements of their role.

Background

The complexity of assuming the role of caregiver can be analyzed through Afaf Meleis' Theory of Nursing Transitions (Schumacher & Meleis, 1994). According to this theory, 'transition' is defined as the process of incorporating changes in the way of living while simultaneously redefining the way of being of the individual experiencing the transition. Transitions can be related to health-illness, situational, developmental, or organizational changes. At the individual and family level, transitions involve changes in identity, roles, relationships, skills, competencies, and behaviors. Success in these transitions may be influenced by various conditions/ factors, such as meanings, beliefs and expectations, level of knowledge, preparation and planning, and the environment. Schumacher and Meleis (1994) point out the evidence of role mastery, subjective well-being, and well-being of relationships as indicators of a successful/ healthy transition.

Considering that taking on the role of caregiver is a situational transition, the requirements inherent to the role can relate to facilitating conditions and personal needs, particularly in preparing and knowing how to achieve healthy response patterns for the role of caregiver. However, the personal conditions, requirements, demands for action, and resources needed for caregiving vary depending on the person being cared for (Melo et al., 2014). Nunes et al. (2019) identify previous caregiving experiences, spirituality and religion, family support, and health networks as facilitators for transitioning into the role of caregiver.

Assuming the role of caregiver is a commitment that can be challenging, not only due to the requirements of the role but also because of the impact it has on the caregiver and the family as a whole (Martins et al., 2016; Swartz & Collins, 2019) as limitations may arise due to lack of availability, goodwill, or proper functioning of home support services or access to healthcare institutions (Machado, 2013).

The process of transitioning to the role of caregiver can develop slowly and progressively, in which case the person being cared for slowly and progressively becomes dependent, or suddenly, after a dependency-generating event. In the latter case, Machado (2013, p. 62) points out that "the process of caregiving does not result from a well-thought-out decision, made with the necessary information to understand the real magnitude of the role". Taking on the role of caregiver for a dependent person causes behavioral changes within the family, and assuming this responsibility can cause the caregiver to distance themselves from other family members (Machado, 2013).

Taking on the role of caregiver as a healthy transition relies on the commitment to the role, the needs of the caregiver according to the condition, and the needs of the dependent person. Thus, recognizing the requirements on the part of the caregiver may guarantee a successful transition (Meleis, 2010), with Schumacher et al. (1998) also emphasizing the importance of understanding the caregivers' perspective.

Therefore, gaining insight into these perceptions through the voice of caregivers fills a gap in the scientific literature, as noted by Nunes et al. (2022).

Research question

What are caregivers' perceptions of the requirements of their role?

Methodology

To achieve the study's objective, a qualitative, exploratory, and descriptive research was conducted, using a convenience sample (non-probability sampling method), consisting of caregivers of dependent individuals receiving home care from a hospital in the Central Region of Portugal.

Data were collected between January and March 2023, following a favorable opinion from the Ethics Committee (Opinion No. OBS.SF.245-2021) and in compliance with the fundamental ethical principles to be considered in research involving human subjects (Declaration of Helsinki), namely the right to self-determination, privacy, anonymity and confidentiality of personal information, as well as the use of informed consent.

The data were gathered through semi-structured interviews, using a script developed for this purpose, which described the participants' characteristics and included the following questions: Can you discuss your family member's experience and situation of dependency from the caregiver's perspective? Explain the requirements that you, as a caregiver, need to fulfill considering your family member's health situation. Describe what you consider to be the most important aspects of performing the role of caregiver. Identify which care guidelines received from the nurses at the moment of hospital discharge you find most useful. Two interviews were conducted with two caregivers not included in the sample to validate the interview script. These interviews were used to verify the clarity of the questions, language, and compliance with the study objectives. The script was also reviewed by experts in the field. Before conducting the interviews, the procedures were trained and standardized.

Data were collected until data saturation was reached (Guest et al., 2020). After obtaining informed consent, the interviews were conducted with the caregivers at home during the home visit scheduled by the hospital. The interviews were audio-recorded and transcribed in full. To maintain data confidentiality, participants were identified using the letter I (I = Interviewee) followed by the sequential number assigned to their interview.

The data were processed using Bardin's (2020) content analysis model. Bardin proposes a four-phase approach to data treatment: pre-analysis, material exploration, classification and categorization, and inference. Pre-analysis involves organizing the material for analysis. Material exploration involves transforming and compiling raw data into units of meaning and categories. Classification and categorization involve differentiating the constituent elements of a set and regrouping them by analogy according to previously defined criteria. Inference allows moving from the description phase, which summarizes the characteristics of the text after treatment, to interpretation, which attributes meaning to these characteristics. This process was supported by the MAXQDA Analytic Pro 2022 software.

The results were evaluated based on the criteria of credibility, transferability, dependability, and confirmability in order to guarantee the quality of the study (Lincoln & Guba, 1985). To ensure credibility, the results of the content analysis were confirmed with four study participants. The transferability was confirmed by presenting the results of the research to two experts in the field who did not participate in this study. Dependability was ensured through reviews by a researcher with extensive experience in qualitative research who was not involved in the study. Finally, confirmability was established by comparing our results with those found in other studies. The criteria for rigorous qualitative research were applied throughout the development of our study, and this article is structured according to the COREQ (COnsolidated criteria for REporting Qualitative research) guidelines.

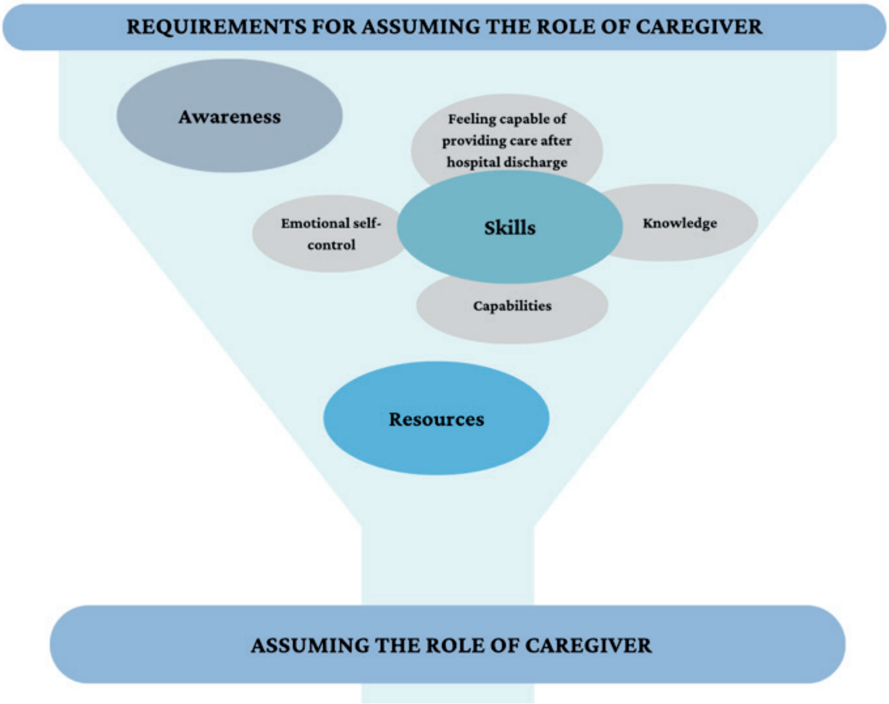
Results

The study presents the results of nine interviews conducted with caregivers of individuals who required home nursing care after being discharged from a university hospital in central Portugal. The participants included seven women and two men, with a mean age of 65.56 years (ranging from 50 to 76 years). Three of the caregivers were caring for their parents, while six were caring for their spouses. In five of the cases where the caregivers were caring for their spouses, the household consisted only of the couple. Four of the caregivers in the sample had only basic education. Additionally, four participants had other professions while five were already retired. None of the caregivers had prior experience in caring for a dependent person, and all had been in this role for two months or less, ranging from two weeks to two months. Regarding support, the caregivers received no professional assistance other than the Home Care Service, which had a limited duration. Two participants received help from neighbors, and two others received help from family members.

The analysis revealed the organization of the phenomena into three categories and their subcategories: (1) Awareness; (2) Skills, ([I] Feeling capable of providing care after hospital discharge; [II] Knowledge; [III] Capabilities; [IV] Emotional self-control); (3) Resources (Figure 1).

Figure 1

Categories and subcategories of the requirements for assuming the role of caregiver.



(1) Awareness (I3, I6 and I9)

Awareness is related to the perception and knowledge of the changes taking place. The participants recognized awareness as a necessary construct for taking on the role

> . . . she wasn't walking. I only realized that she wasn't walking when she was transferred to the stretcher, and I was like this is going to be even more complicated than I thought, I didn't realize that my mother wasn't walking. After she came home, I began to have a different perspective on what it was going to be like and that it was going to be very complicated. It wasn't until then . . . (I6)

"I hadn't thought about it yet. Only when he arrived. I thought he was going to be stronger, more autonomous" (I9).

(2) Skills

Four subcategories emerged within the Skills category: Feeling capable of providing care after hospital discharge; Knowledge; Capabilities; and Emotional self-control.

(I) Feeling capable of providing care after hospital discharge (I1, I2, I3, I4, I5, I6, I8, and I9): Preparing the caregiver to provide care after the hospital discharge of the person they will be caring for is a process led by the health team that should be implemented from the moment of hospital admission to the moment of hospital discharge. The participants reported the need to receive training for assuming the role of caregiver at the time of hospital discharge

> They gave me information because I demanded information, I asked all the questions I could think of at the time and . . . they gave it to me and yes, that's it . . . because I asked, I don't know whether they would have explained so much to me if I hadn't asked, right? I have the feeling that maybe they wouldn't and so you go home without knowing what to do . . . (I3)

> At the hospital, sometimes I'd talk to the nurses there and they'd also tell me ... now you have to do it like this, they also explained it to me more or less... They also explained it to me more or less . . . but of course, explaining is one thing, me doing it is another . . . (I5)

". . . they only mentioned how to put the dorsolumbar support on." (I6), "What they taught me . . . was how to get him to walk and walk . . . that's it. What they taught me was mostly the motor part, the physical part . . ." (I8).

(II) Knowledge (I1, I2, I3, I4, I5, I6, and I8): This subcategory highlights the knowledge that caregivers have about caring for the dependent person. It is a requirement and, consequently, an essential mastery indicator in this process. The participants identified their knowledge of the therapeutic regime:

> The medication is the usual medication . . . he's just taken half a pill for his blood pressure . . . and now he's going to take . . . in the morning he only takes this... then in the evening, at dinner, he takes olanzapine, he now takes 7.5 mg instead of 5 mg . . . because of those things . . . those ideas he has . . . and he takes aspirin and then . . . and then he also takes seroquel . . . it was prescribed by a psychiatrist . . . and he also takes a pill that I buy in the pharmacy, which is natural . . . (I1),

the prevention of complications for the caregiver and the person being cared for “It was about whether she could bend her leg, it had to be stretched out all the time, and since she had staples, she didn’t know how she could deal with it, whether she could or should start moving . . .” (I4), sleep and rest, and care to respond to self-care dependency as requirements for taking on the role of caregiver

> Information on how to treat the patient, information on what the prospect of improvement is, and information on how much I can demand of the patient, I want her to get better but I can be demanding too much and exercise, demanding that she does this or that, well I don’t demand anything, to what extent do I . . . that information, that information, more . . . grounded, more rigorous information on how to care for the patient” (I3).

(III) Capabilities (I1, I2, I3, I4, I5, I6, I7, I8 and I9)

The participants highlight as requirements the caregiver’s capabilities in the different domains of care (self-care, bodily and psychological processes). The caregivers mention being capable of managing the therapeutic regimen “From the moment I put her on the sofa, I started looking after her, giving her insulin and the morning pills” (I6), self-care “At the moment I help with hygiene, dressing, walking, moving back and forth, and that’s it, essentially . . . ” (I3),

> Bathing, helping her get dressed, also going to the toilet during the first few days . . . now she’s starting to manage on her own, but I also had to go with her to the toilet . . . (I5),

promoting autonomy/independence

> . . in the morning I help him with his hygiene, and little by little he’s trying to gain some autonomy. . . Then I help him get dressed, and little by little I’ve been forcing him, forcing him figuratively speaking, to try a bit more (I7),

preventing complications

> I had to walk with her, of course . . . in the first . . . in the first 15 days that we . . . that she came out, we had to walk behind her because she could fall . . . (I5)

and physical strength “Because my strength is also . . . I’m already 75, I’m not young either . . .” (I2), “. . . it’s innate in me, I’m a strong person. . .” (I3),

> . . if you don’t feel strong . . . I tell you, sometimes I lower myself to put on her shoes or her socks, and I’m … when I get up, I seem to be worse off than she is . . . I’m like this . . . I see everything . . . I have my problems, too . . . (I5),

“I don’t have a lot of strength. . .” (I8).

(IV) Emotional self-control (I1, I2, I4, I5, I6, I7, I8, and I9): The participants consider emotional self-control, such as being able to manage emotions and adopt strategies, a requirement for taking on the role of caregiver. They mention the ability to manage emotions

> For me, the biggest problem I have is that he’s often . . . constantly calling . . . calling, calling, calling and sometimes I go haywire . . . sometimes I can’t even stand him listening to me, or I listening to him (I1), “. . . I’ve been very optimistic all along” (I4), “. . . I want him to get out of bed. He doesn’t want to. He wants to lie down. And I yell at him. Sometimes I lose my temper and I lose . . . Patience” (I8), and adopt coping strategies as a requirement for taking on the role of caregiver “. . . I used to go to the swimming pool, to the gym . . . now and then I would go dancing a bit, go for walks . . . And, psychologically, I have to go out from time to time ... (I1),

“. . . it’s God our Lord who gives me the strength to . . . gives me a lot of, how should I say, a lot of energy.” (I2).

(3) Resources (I1, I2, I3, I4, I5, I6, I7, I8, and I9)

Resources refer to the material, financial, community, and other means of support to which caregivers can access. The participants mention as requirements the access to technical aids “he has a walker, he uses the walker” (I2), “When he arrived here, I already had the walker, and the crutches, we only used the wheelchair when he arrived, then we never used it again” (I7), architectural resources “he has supports, doesn’t he? On the wall, in the bathroom, here . . . even outside, so he can get up . . . generally, he moves around in the wheelchair . . . ” (I1), “It took a while because the bathrooms now aren’t prepared . . . the houses are 30 years old” (I2), community resources “Having someone to help us, having someone to help us” (I2), “I didn’t know there was this resource in the hospital” (I3), “They come here . . . once or twice a week to do a bit of physiotherapy . . . ” (I5), “. . . there’s the health center, I have everything at hand here . . . thank God, I have the pharmacy here.” (I8), financial resources “Look, financially, fortunately . . . before he was well, and we didn’t have what we have . . . financially, we have no difficulties” (I1) and availability (time) “What is more difficult for me is that I actually have to dedicate a lot more time. I have to be present at home” (I3),

> If I had to work, it would be impossible, I do everything, I’m with him, but if I was working, I would have to ask for a leave of absence and I don’t know what that is like now, because they’re going to give it to me, I don’t know if they’re going to discharge me or not at the medical board, but I’ve learned to live one day at a time. (I7)

Discussion

Assuming the role of caregiver for a dependent person can often be unexpected, leaving the caregiver with little to no prior knowledge, preparation, or experience. During this process, the caregiver may not fully recognize the challenges, difficulties, and future needs associated with caring for a dependent person (Machado, 2013).

According to Meleis’s Theory of Nursing Transitions, taking on the role of caregiver demands that the person experiencing the transition acquire/ develop new knowledge and skills, adopt new behaviors, and adapt to a new social identity (Chick & Meleis, 1986; Meleis 2000). Understanding what to expect during this process, the strategies to employ, and the potential outcomes are regarded as the catalysts for a healthy transition (Meleis & Trangenstein, 1994).

In our study, participants identified "Awareness" as necessary for assuming the role of caregiver, showing that the internalization of the difficulties and associated changes occurred when their relative returned home: "After she came home . . . it was going to be very complicated" (I6). Meleis (2000) considers awareness to be a property of transitions reflected in the degree of congruence between the knowledge of the process and the reactions and perceptions of the individuals experiencing the transition. This property is a requirement for assuming the role, and the person is expected to be aware of what has changed and its implications. However, a lack of awareness does not indicate that the person has not started transitioning to the new role. In line with Machado (2013), the findings of our study suggest that the assumption of the role of caregiver often occurs without awareness: ". . . she wasn't walking. I only realized that she wasn't walking when she was transferred to the stretcher . . ." (I6), "I thought he was going to be stronger, more autonomous" (I9).

The training of caregivers by nurses is essential for developing competencies, including knowledge acquisition and skill development related to the role of caregiver (Schumacher et al., 2000). Machado (2013) observed that nurses underscored the short period of time between the occurrence of the dependency-generating event, hospitalization, and discharge for caregiver preparation, pointing to the need to systematize essential requirements for the optimal development of the process of transition. The subcategory of "Feeling capable of providing care after hospital discharge" emerged from the interviews, based on units of meaning describing the gaps in the caregiver's training for hospital discharge and highlighting the need they felt for home care training: "I don't know whether they would have explained so much to me if I hadn't asked" (I3). According to Lutz et al. (2011), the inadequate preparation of the caregiver for discharge is considered a second critical event, in addition to the illness process itself. In a subsequent study, the same authors identified gaps in the caregiver's training for discharge and assumption of their role as home caregivers (Lutz et al., 2017). The lack of caregiver's preparation for discharge may be due to nurses focusing more on the dependent person than on the caregiver, indicating that this area calls for a different conceptualization on the part of these health professionals and, consequently, a redoubled focus (Nunes et al., 2022).

According to the theoretical framework mentioned above, personal conditions such as level of preparation, knowledge, and skills facilitate the transition (Chick & Meleis, 1986; Meleis, 2000; Meleis & Trangenstein, 1994). Having the knowledge to make decisions and the skills to manage this new role is crucial to taking on the role of caregiver. The units of meaning included in the Knowledge subcategory (I1, I2, I3, I4, I5, I6, and I8) show that caregivers value knowledge as important for assuming their role, particularly in the areas of therapeutic regimen, prevention of complications, sleep and rest, and care to respond to the self-care dependency of the dependent person. Grounded in knowledge, the respondents identify skills in managing the therapeutic regimen, self-care, promotion of autonomy/ independence, prevention of complications, and physical strength as requirements for this new role. According to Lutz et al. (2017), caregivers must learn strategies to meet the needs arising from this process to avoid the potential detrimental effects of assuming this role.

Assuming the role of a caregiver requires not only cognitive abilities but also emotional abilities. The participants noted that managing emotions and utilizing coping strategies are necessary for becoming a caregiver, specifically in the subcategory of Emotional self-control (I1, I2, I4, I5, I6, I7, I8, and I9). According to the ICN (2006), these skills are considered to be indicators of a healthy transition process in which people show increased knowledge, understanding of what they are experiencing, and the ability to cope with the difficulties/challenges they face. In this context, the necessary skills to take on the role of a caregiver include knowledge, skills, and emotional self-control.

According to Meleis (2000) and Meleis and Trangenstein (1994), personal conditions, particularly socioeconomic status, in interaction with community and societal factors, are also potential facilitators or inhibitors of a healthy transition. The participants identified several resources (I1, I2, I3, I4, I5, I6, I7, I8, and I9) as necessary for caring for a dependent person. These resources include technical aids, architectural resources, community resources, financial resources, and availability (time), confirming the conditions described in the theoretical framework as facilitating transitions. Hence, our study's findings suggest that favorable socioeconomic conditions, the presence of a caregiver support network, and rest for the caregiver are facilitating resources for taking on the role of caregiver, in line with that observed by Nunes et al. (2022).

Our study has limitations, namely the sample's type and size, the complexity of the phenomenon under study for the participants interviewed, and the fact that the results may not fully reflect the requirements for assuming the role of caregiver.

Conclusion

Based on the obtained results, the use of qualitative research methodology proved appropriate for the development and accomplishment of the initially outlined objective. This methodological approach allowed us to learn about the caregivers' perceptions of the requirements for assuming their role: Awareness; Skills (Feeling capable of providing care after hospital discharge, Knowledge, Capabilities, and Emotional self-control); and Resources. In terms of implications for clinical practice, our study can help to improve the assessment of the caregiver's caregiving potential and identify the conditions that facilitate or hinder the assumption of this role. Based on the state of the art and the findings obtained, future studies should focus on nurses' perceptions of this phenomenon.

Author contributions

Conceptualization: Santos, E. J., Lopes, M. B., Manata, J., Santos, D., Limão, R., Nunes, M. C.
Data Curation: Santos, E. J., Lopes, M. B., Manata, J., Santos, D., Limão, R., Nunes, M. C.
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Validation: Nunes, M. C.
Writing – Original Draft: Santos, E. J., Manata, J., Santos, D., Limão, R., Nunes, M. C.
Writing – Review & Editing: Santos, E. J., Lopes, M. B., Limão, R., Nunes, M. C.

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