



ORIGINAL ARTICLE

Informal caregivers' perceptions of their health activities during home hospitalization*

HIGHLIGHTS

1. Caregivers reproduce prescriptive guidelines from the healthcare team.
2. We suggest implementing a hospital-home care transition program.
3. Caregiver support is needed, considering their individual needs.

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ABSTRACT

Objective: To understand the perceptions of informal caregivers with up to six months' experience about their health activities during home hospitalization. **Method:** This qualitative study was conducted through interviews with primary caregivers of people registered with the Home Care Service in a region of the Federal District of Brazil who had been admitted for up to six months. Data were collected between July and October 2022. The data were analyzed using Bardin's Thematic Content Analysis. **Results:** Three thematic categories were identified: health activities performed by caregivers, caregiver perspective on caring at home, and caregiver knowledge trajectory. **Conclusion:** The findings point to the need to implement a transition program from hospital to home care, as well as intersectoral actions and public policies that can provide a support network for caregivers and consider their individual needs.

DESCRIPTORS: Home Care Services; Home Nursing; Caregivers; Home Health Nursing; Home Health Aides.

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INTRODUCTION

Demographic and epidemiological changes marked by population aging and the consequent increase in the prevalence of chronic conditions require a reorganization of health services, focusing on Home Care (HC)¹⁻². In Brazil, through Ordinance No. 825 of April 26, 2016, the Brazilian Ministry of Health redefined the concept of HC as a type of care involving services for treating diseases, rehabilitation, palliative care, disease prevention, and health promotion actions³.

HC is organized into three levels: HC1, HC2, and HC3. At HC1, care falls within the remit of Primary Health Care and includes users with a lower frequency of care. The second and third levels (HC2 and HC3) are the responsibility of the Home Care Service (SAD) and require more complex and frequent care³.

Users classified as HC2 are those diagnosed with acute or chronic acute illnesses requiring intensified and sequential care; chronic-degenerative diseases, depending on the degree of impairment caused by the illness; the need for palliative care with at least weekly clinical monitoring; or prematurity and low birth weight in babies requiring weight gain. Users eligible for the HC3 modality are those with any situations listed in the HC2 modality and intensified demands³.

Among the criteria previously established for inclusion in this type of care, it is essential to have a caregiver responsible for daily care under the guidance of the health team⁴⁻⁵. This caregiver can be a person with or without family ties to the user, who must help them with their activities of daily living and must be the communication link with the home care team^{3,6}.

In this document, we have chosen to call the person registered for home hospitalization a patient since both the caregiver and the patient are SUS users.

According to the Brazilian Institute of Geography and Statistics (IBGE, in Portuguese), 49.1 million people in Brazil cared for people at home in 2019; however, no records were found of the number of caregivers of people in home hospitalization in the country⁷.

Considering the above, this research is justified by the need to get closer to caregivers' daily lives, considering the persistent difficulties they present in transitioning from hospital to home care. The question is: What are these caregivers' perceptions of their routine actions about the person dependent on care? In this way, this study aimed to understand the perceptions of informal caregivers with up to six months' experience of their health activities during hospitalization at home.

METHOD

This is a descriptive, exploratory study with a qualitative approach, carried out in a SAD setting of the Unified Health System in a region of the Federal District - Brazil, at the Regional Home Care Center (NRAD, in Portuguese), with 101 registered patients.

The study participants were the caregivers of people registered at this NRAD. The inclusion criteria were to be the primary caregiver⁸ of the person in-home care within six months of admission, which means people who generally remembered in detail the process

of registering with SAD and who were aware of recent adaptations. The exclusion criteria were caregivers who had a health degree or a caregiver course. All the caregivers who met the criteria and were invited to participate in this study were accepted; however, two of them were excluded because, during the interview, they reported coming from another NRAD, so they had been caregivers for more than six months.

Based on the list of patients' caregivers provided by the health team and the admission period, the likely participants were invited to participate in the research when they came to the basic health unit or by telephone. They were then presented with the study's aim and the risks and benefits of taking part. Once they had accepted, the interview was scheduled according to the availability of the date, place and time of each participant, and the Free and Informed Consent Form (FICF) was signed, as well as the Term of Assignment for the Use of Voice Sound.

Data was collected by the researcher in charge, a nurse with appropriate training in qualitative interviewing, between July and October 2022. Because they were primary caregivers, the participants chose to be interviewed at home. However, the interview took place in an environment that maintained the privacy of the participants and the confidentiality of the information shared. The caregivers' sociodemographic data were collected using an instrument that included age, gender, schooling, family income, marital status, and type of relationship with the patient.

The interview lasted an average of thirty minutes and was guided by the following question: describe how you care for the person under your responsibility who is hospitalized at home. Throughout the fieldwork, the researcher recorded her impressions of the object of study in a field diary.

The total number of ten participants was reached based on the criterion of theoretical data saturation. Closing the sample due to theoretical saturation is defined as suspending the inclusion of new participants when, in the researcher's opinion, the data obtained becomes redundant or repetitive, and it is no longer considered relevant to continue collecting data⁹.

After receiving training, a nursing student transcribed the interviews in full. The researcher in charge checked the transcripts with the audio recordings of the interviews to ensure the integrity of the data, and the sociodemographic variables were tabulated in a Microsoft Excel Office® spreadsheet. The research data was stored on the researcher's computer. To identify each file, anonymity and confidentiality were protected using the letter I (interview), followed by Arabic numerals in ascending order.

In analyzing the participants' speeches, we used thematic content analysis¹⁰. In this way, the transcripts of the interviews were read gloatingly and exhaustively, the summaries prepared were grouped, and thematic categories emerged. This was followed by inference, interpretation, and discussion with other studies found¹¹.

The observations recorded in the field diary were read horizontally, identifying the data that stood out. Then, the information was synthesized and arranged so that it could dialogue with the participants' statements.

Under opinion no, the study was approved by the Ethics Committee (CEP) of the Faculty of Health of the University of Brasília (UnB). 5.287.177/22 and by the CEP of the Foundation for Teaching and Research in Health Sciences (FEPECS) under opinion no. 5.405.132/22.

RESULTS

The following parameters were summarized: age, gender, schooling, marital status, family income, relationship with the patient, degree of patient dependency, permanent invasive device, and presence of a pressure injury, as described in Table 1.

Table 1 - Characterization of the participants' situation. Brasília, DF, Brazil, 2022

Parameter		n	%
Age	25-29	1	10
	30-39	2	20
	40-49	1	10
	50-59	3	30
	≥ 60	3	30
Gender	Female	9	90
	Male	1	10
Education	Incomplete elementary education	2	20
	High school incomplete	2	20
	High school complete	3	30
	Higher education incomplete	2	20
	Higher education complete	1	10
Marital status	Single	3	30
	Married	6	60
	Divorced	1	10
Family Income (No. of minimum wage*)	≤1	4	40
	1-2	4	40
	≥3	2	20
Relationship with patient	Son	4	40
	Mother	2	20
	Spouse	1	10
	Niece/Sister	2	20
	Friend	1	10
Degree of dependency (patient)**	Total dependence (Grade 5)	9	90
	Partial dependence (Grade 1)	1	10
Device Invasive Permanent (patient)	Tracheostomy	2	20
	Tube	8	80
Presence of a pressure injury (patient)	Yes	6	60
	No	4	40

*Minimum wage according to Law 14.358 of June 1, 2022¹²

**Dependency level according to the Spanish Red Cross Scale¹³

Source: The authors (2022)

CONTEXT OF CAREGIVERS IN HOME HOSPITALIZATION

The participants discussed the actions and adaptations of the home care routine, the feelings and difficulties involved in the situations they faced with the patients, and the process of learning the activities they carried out daily.

Thus, three categories emerged from the qualitative analysis of the interviews: *Health activities performed by caregivers, caregivers' perspective on caring at home, and Caregivers' knowledge trajectory.*

In the *Health activities carried out by caregivers*, the caregivers mentioned the activities carried out by the person under their responsibility. They highlighted body hygiene, skin care, device management, and helping with patient mobility, medication administration, and diet.

(...) I'm bathing him in bed, but from now and then (...) we take him to the bathroom for a more thorough bath, you know? Because bathing in bed is never the same as bathing in the bathroom (...). (I5)

(...) No column can cope, either. It's also a huge responsibility to pick someone up like that. Can you imagine if they fall? God forbid, right?" (I6)

First, you remove all the previous dressings, and if there is any feces, you have to be really careful to remove it so you don't get feces into the wound. Use... (...) "From what you've learned" gradually. Step by step, applying the medication that has been... That's what we're trained for." (I7)

(...) That's when you put it in the tracheostomy first and then in the mouth because that's how it was (...) taught. Then she sucks on it. Then, sometimes, she coughs, and something comes out. Then, when she's coughing, I take the hose off. " (I10)

The category "*Caregiver's perspective on home care*" brought together caregivers' accounts of the changes they experienced when they started providing home care and their difficulties. Some reported that it was essential to learn how to carry out the procedures, considering that they were the only ones responsible for the activities with the patients and that they often felt frightened.

(...) It changes our routine a lot. The routine of being unable to go out, sometimes there are things to sort out, including her own, right? (...) We had a hard time. (...) It weighed on us. Especially because I had the house here, I have my husband and a lot of stuff to sort out, right? (I1)

Everything was difficult for me. The worst moment was when I had to come home with [him]. Everything they say to me is easy for them, as they already know, but not for me. So, it was difficult for me to start. Having to do it alone. I was afraid. (...) It was me or else, you know? (...) If I don't do it, so what? [...] if I don't do it, [he] dies, so... (I3)

According to the interviewees, becoming a caregiver often occurs abruptly so that health professionals mediate the development of the skills needed to care for a dependent person.

(...) There are details that you only get with routine... (...) It would be best if you really practiced learning the ropes, don't you? (...) They taught me at NRAD. (...) Then

I went there, and they said: "So, no... You do this, this and this." They gave me some guidelines, right? (...) She did the dressings. I saw her doing it herself, and she explained it, right? (...) Now, we're in heaven... the storm is over, in a way. (I1)

We followed the nurse around the hospital. They taught us. They explained it to us. So, when we came home, we came with all the instructions (...). The NRAD team also helped us a lot (...) (I2)

DISCUSSION

The participants in this study reflect characteristics identified in the literature, especially the prevalence of women¹⁴⁻¹⁶. This aspect reinforces the gender issue associated with domestic activities and the role of caring, a condition naturalized by society¹⁶⁻¹⁸. In addition, according to other studies, the unemployment and low income of the participants reinforce the fact that caring for a person at home means they must leave their formal jobs and, consequently, many of them become dependent on social benefits or the retirement pension of the person they care for¹⁶.

Regarding schooling, the time spent in formal education is related to the ability to assimilate knowledge about disease and develop caregiving skills¹⁴. However, a more significant number of years of schooling may not be reflected in health decision-making and understanding of the activities to be carried out by the caregiver.

According to the Ministry of Health, the primary duties of caregivers include helping with hygiene care, stimulating and helping with feeding, helping with locomotion and physical activities, changing positions in bed and the chair, and administering medication as prescribed and guided by the health team⁶. So, as you know, the performance of these activities does not characterize the caregiver as a health professional. Therefore, they should refrain from performing technical procedures that fall within the competence of professionals, such as administration of parenteral medication, dressings, and placement of tubes⁶.

According to Law 7.498/86, nursing care of greater technical complexity, requiring adequate knowledge and the ability to make decisions, is the sole responsibility of nurse¹⁹. Therefore, the caregiver's role should not involve performing techniques that are the preserve of health professionals, in this case, complex dressings⁶.

Ordinance 825/20163 stipulates that the SAD teams must provide care at least once a week, but situations that require complex care beyond the standardized minimum, such as dressings and changing tubes on unforeseen occasions, can be challenging to attend to due to the temporary or permanent unavailability of human and/or material resources. Some issues could be perceived and were recorded in the field diary, such as the availability of only one vehicle and one driver for each unit. From this perspective, home hospitalization in the public network often places caregivers in circumstances that require them to be prepared to deal with complex care procedures, as found in this study, such as dressings^{3,20-23}.

In line with these findings, a study in Australia stated that patients and caregivers are responsible for monitoring the transfer from hospital to home care²⁴. Thus, caring for a person in a hospital at home imposes many changes in the lives of family members, especially caregivers, who may neglect self-care²⁵.

Thus, in addition to providing information about actions that favor the well-being of the person being cared for, it is necessary to think about self-care for these people since the quality of life can have a direct influence on the activities performed, including achieving better health results for the person dependent on care²⁶. This aspect is worth highlighting since the home care team systematically focuses on the patient.

Among the main difficulties encountered by caregivers are activities that require physical effort⁸. Many interviewees pointed out challenges in mobilizing the people they care for. This unpreparedness predisposes them to back pain and spinal problems, the latter being the most frequent complaint¹⁷. Given this, knowledge of ergonomic techniques is indispensable and even allows caregivers to prevent injuries. Professionals should guide caregivers, including activities that seem simple to them, such as changing decubitus, changing diapers, and bathing, as well as the ergonomics involved in carrying out these procedures²⁶.

In addition, to care for a care-dependent person at home, caregivers generally need to adapt the home's infrastructure and plan, provide, and acquire the materials they need to carry out the care.

Family dynamics are also changed, as there is a need to meet new demands on behalf of the sick person, resulting in a redefinition of roles and postponement of life projects. The participants in this study revealed that these changes are often veiled. And it puts the person the family expects to be the caregiver to the test. It was not described as a negotiated or dialogue process. In the interviews, some caregivers even pointed out the strain on other family members due to their distance from the patient.

In addition, the lack of choice in performing this role, the centralization of care in just one or a few people, the responsibility for carrying out various household chores, and the degree of dependence of the person being cared for all contribute to the caregiver's overload. It should also be noted that most of the participants in this study were related to the person being cared for, which also contributes to the burden, as found in other studies^{8,18,27}.

In addition, caregivers must acquire the knowledge and skills to meet the basic needs of the person under their care who is hospitalized at home. Generally, caregivers begin to get closer to the procedures required by the patient during hospitalization. However, this experience does not take place systematically and sufficiently to provide security for caregivers²⁶, as demonstrated in the statements of the participants in this investigation.

In this way, the initial phase of constructing the role of caregiver triggers various feelings, such as fear of being unable to carry out the procedure or of something happening during it²⁸, issues also demonstrated in the participants' speeches.

The participants in this study perceived caring at home as related to their negative feelings, such as fear, powerlessness, and insecurity. At the same time, they did not question how they were prepared or not prepared for this purpose.

In this sense, there is an incidence of silence that expresses the occurrence of a problem: users of the public health system don't know their rights properly or choose not to claim them²¹. In practice, few users claim their rights.

Although there are public policies aimed at home hospitalization and the public health system partially takes over SAD care, there still needs to be known actions aimed at caregivers since they are not recognized as active subjects in managing care^{16,23,27}.

In this respect, caregivers reported that they learned how to provide care by observing the procedures performed by the healthcare team during hospitalization/at home rather than through specific training. This finding was also highlighted in another study carried out with primary family caregivers of care-dependent elderly people²⁷.

It turns out that training caregivers while still in the hospital environment, combined with monitoring and supervision by the home care team, increases therapeutic adherence and reduces the need to call emergency services and hospital readmissions due to inadequate care²⁹.

This study observed that the caregiver training process occurs predominantly through the team repeating commands and checking that these prescriptions are understood at each home visit. In addition to prescriptions and guidance, the home care team routinely performs procedures in the presence of the caregiver, making it possible to repeat care actions³⁰. Thus, the reproduction of care observed and/or learned by caregivers shows attitudes fed by prescriptive practices and vertical educational actions adopted by health professionals³⁰.

Several guidelines need to be followed by caregivers, especially during the process of care transition (hospital-home), which requires constant learning and intensified monitoring by the team. During this period, caregivers find it more difficult to absorb the volume of information and feel insecure³⁰. For this reason, caregivers with up to six months of experience were prioritized to gain an understanding of this transition.

Therefore, in addition to verbal guidance, studies suggest that written information, illustrations, and support materials provide a better level of fixation and allow the user to revise if necessary^{14,30}. The participants in this study should have provided no information about the existence of support materials offered by health professionals or even by a website available on the internet. As a result, home care professionals should welcome caregivers in their difficulties, making room for other forms of health education that value subjectivity and meet individual needs according to the family's social and cultural context²⁹⁻³⁰.

Therefore, compliance with the recommendations of the patient's de-hospitalization process must consider the needs and particularities of the caregiver to ensure a safe transition not only for the dependent person but also for their caregiver²⁶. This makes it necessary to design and implement a program for the transition from hospital to home care.

Therefore, the home care policy clarifies the potential of hospitalization at home, both for the family's and the SUS's benefits. However, this study points to the possibility of alignments that require analysis in other realities to support the adaptation of public policies.

Regarding the limitations of this study, I want to point out that the primary caregivers were not available to be interviewed at the unit, so they opted to be interviewed at home. As a result, some interviews were interrupted due to the need to attend to the patient or other demands at home. Some people, such as animals, were interfered with by domestic noise. However, they were all resumed on the same day and simultaneously, without any detriment to data collection. This limitation also reveals itself as a fact of this study since these caregivers find it extremely difficult to focus on an activity due to constant interruptions, even when they consider that the demands of the person dependent on care have been met.

FINAL CONSIDERATIONS

The results show that the proposed objective has been achieved, as they revealed the caregivers' perceptions of the health care they provide during home hospitalization. Considering the importance of this role in the continuity of care for patients at home, this study points out the potential and weaknesses of health care. It highlights the importance of valuing the caregiver as the protagonist in managing home care and encouraging self-care.

This study showed that caregivers' preparation is predominantly based on prescriptive guidance from the health team in a non-systematized way, which can interfere with the quality of care they provide.

By identifying the challenges experienced in the transition from hospital to home, the findings can guide the design and implementation of a care transition program, starting with the de-hospitalization process, with other forms of health education, in addition to verbal guidance, as well as public policies that provide a support network for the caregiver and consider their individual needs.

Thus, this research suggests further studies that point to the results of caregiver training interventions during the transition from hospital to home care.

In addition, the caregivers did not question how they were trained to care for a person in the home, nor did they question carrying out complex procedures, even in the face of their negative experiences. Therefore, the data obtained through this study is proposed to substantiate home care management.

Finally, getting closer to caregivers' daily lives has allowed us to rethink the context of home hospitalization from the moment a person reaches the criteria for admission, signaling ways to reorganize the work process, implement public policies aimed at caregivers, and take intersectoral actions that can provide quality of life and safety for the person being cared for and their caregiver.

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