

Experiences of family caregivers in the home care to people with pressure injuries

Experiência de familiares no cuidado à pessoa com lesão por pressão no domicílio
Experiencia de cuidadores familiares de personas con lesiones por presión en el hogar

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Abstract

Objectives: To analyze the experience of family caregivers in the home care for people with pressure injuries (PI). **Methods:** Qualitative and descriptive research carried out with family members who received support from the home care service and who were the main informal caregivers of people with PI from stage 3 onwards. A sociodemographic questionnaire and semi-structured interview were applied with the following stimulus for narration: tell me about your experience in the home care to your family member with PI? Data were analyzed according to Bardin's content analysis. **Results:** Four categories emerged: 1) Performance of family members in PI care; 2) Support of the home care service to the family and patients with PI; 3) Overload of family caregivers; 4) Satisfaction in repaying the care received. **Conclusion:** This study showed the importance of support to home care service and the difficulties experienced by family members in caring for people with PI, including financial and physical overload; lack of preparation of the caregiver to deal with PI; family conflicts; and the centralization of care responsibility, predominantly performed by women. However, many see in care the opportunity to return the love received, despite all physical and mental fatigue.

Descriptors: Pressure injury; Caregivers; Family; Home care services.

What is already known on this?

Caregivers need to be sensitive to their needs and insecurities when caring for bedridden family members, as they are constantly exposed to physical, mental and emotional stress.

What this study adds?

This research contributes to rethinking care strategies in HC services, focusing not only on the patients, but also on caregivers.



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Resumo

Objetivos: Analisar a experiência de familiares no cuidado à pessoa com lesão por pressão (LP) no domicílio. **Métodos:** Pesquisa qualitativa e de aspecto descritivo, realizada com familiares que recebiam suporte do serviço de atenção domiciliar e que eram os principais cuidadores informais de pessoas com LP a partir do estágio 3. Aplicou-se um questionário sociodemográfico e entrevista semiestruturada com o seguinte estímulo para narração: me conte sobre sua experiência no cuidado, no domicílio, ao seu familiar com LP? Os dados foram analisados conforme a análise de conteúdo de Bardin. **Resultados:** Emergiram quatro categorias: 1) Atuação dos familiares no cuidado à LP; 2) Suporte do serviço de atenção domiciliar à família e ao paciente com LP; 3) Sobrecarga dos familiares cuidadores; 4) Satisfação em retribuir o cuidado recebido. **Conclusão:** Esta pesquisa evidenciou a importância do suporte do serviço de atenção domiciliar e as dificuldades experienciadas por familiares no cuidado à pessoa com LP, como: sobrecarga financeira e física; despreparo do cuidador para lidar com a LP; conflitos familiares; e a centralização da responsabilidade do cuidado, predominantemente desempenhado por mulheres. No entanto, muitos veem no cuidado a oportunidade de retribuir o amor recebido, apesar de todo o cansaço físico e mental.

Descritores: Úlcera por pressão; Cuidadores; Família; Serviços de Assistência Domiciliar.

Resumen

Objetivos: Analizar la experiencia de cuidadores familiares de personas con lesiones por presión (LP) en el hogar. **Métodos:** Investigación cualitativa y descriptiva, realizada con familiares que recibieron apoyo del servicio de atención domiciliar y que fueron los principales cuidadores informales de personas con LP desde la etapa 3 en adelante; se aplicó un cuestionario sociodemográfico y una entrevista semi-estructurada con el siguiente estímulo a la narración: cuéntame tu experiencia brindando atención, en casa, a tu familiar con LP? Los datos fueron analizados según el análisis de contenido de Bardin. **Resultados:** Emergieron 4 categorías: 1) Papel de los familiares en el cuidado de la LP; 2) Apoyo del servicio de atención domiciliar a la familia y al paciente con LP; 3) Carga sobre los cuidadores familiares; 4) Satisfacción por corresponder a la atención recibida. **Conclusión:** Esta investigación destacó la importancia del apoyo del servicio de atención domiciliar y las dificultades que experimentan los familiares en el cuidado de personas con LP, tales como: carga financiera y física; falta de preparación del cuidador para lidiar con LP; conflictos familiares; y la centralización de la responsabilidad del cuidado, realizado predominantemente por mujeres. Sin embargo, muchos ven el cuidado como una oportunidad para devolver el amor recibido, a pesar de todo el cansancio físico y mental.

Descriptor: Úlcera por Presión; Cuidadores; Familia; Atención Domiciliar de Salud.

INTRODUCTION

The demand for Home Care (HC) tends to grow in the coming years, due to the increase in life expectancy of the population and the low fertility rate, which has contributed to population aging⁽¹⁾. Associated with this reality, there is a growing number of chronic-degenerative diseases that can often generate limitations and restrictions in the execution of activities of daily living, as well as the loss of autonomy and independence of the individuals.⁽³⁾

According to Ordinance of the Ministry of Health (MH) number 825, of April 25, 2016, HC is characterized by health care with actions to promote, prevent, treat and rehabilitate patients who need care that can be performed at home. HC in the Unified Health System (SUS) has the HC1, HC2 and HC3 modalities, which are classified according to the complexity, the characteristics of the clinical cases and also the frequency of the necessary care.⁽⁴⁾

In order to be effective, HC requires a family caregiver, who can be the spouse, partner or other family member. Being a family caregiver is not usually a service with financial remuneration, however it aims to provide activities such as emotional, physical and/or financial support to another individual who cannot take care of themselves due to illness, injury or disability.⁽⁴⁾ One of the challenges of HC is the prevention and care of patients with Pressure Injuries (PI), since most patients treated by the service are partially or totally dependent.⁽⁵⁾

Pressure injury (PI) is localized damage to the underlying skin and/or tissues, which usually arises at sites of bony prominences or due to the use of medical devices or other artifacts⁽⁶⁾. They directly interfere with the patient's recovery time, in addition to exposing them to other complications, which increase the chances of mortality. They result from intense and/or prolonged pressure associated with shear, and risks increase when added to intrinsic predisposing factors.⁽⁷⁾

The PI is classified based on tissue damage, in addition to the depth of the lesion. According to the National Pressure Ulcer Advisory Panel, the classification includes the following definitions: stage 1 pressure injury when skin is intact, with non-bleachable erythema; stage 2 pressure injury occurs with partial thickness loss of the skin with exposure of the dermis; stage 3 pressure injury is when total thickness loss of the skin occurs; stage 4 pressure injury is a more advanced degree, when total skin loss occurs with exposure of other tissues (muscles, bones and tendons); and, finally, the pressure injury may not be classified is when total thickness skin loss occurs and also non-visible tissue loss occurs.⁽⁸⁾

The family caregiver is not always prepared to care for patients with PI at home, an activity that sometimes becomes the responsibility of a single family member. Long-term dependence in the home environment, challenges and insecurity for care, reflect some of the various difficulties and makes there a greater need for support, adaptation and guidance to the caregiver, especially in the transition from hospital to home.⁽⁹⁾

Studies show that exercising the role of caregiver brings with it some disorders and emotionally sensitive situations. First, there are emotional conflicts and high physical demand related to the act of caring for the other person⁽¹¹⁾. Thus, it is common for caregivers to become socially isolated, suffer from changes and marital dissatisfaction and, consequently, present deficits in physical health and self-care.⁽¹²⁾

In this sense, when identifying this problem of caregiver overload, it is up to the multidisciplinary team to offer support and contribute to the planning of HC services to those individuals who need it, based on care strategies that mitigate the problems addressed.⁽¹³⁾

There is a shortage of studies that address the perspective of family members in the home care of people with PI, in order to know the daily challenges of care. Thus, given the importance of the role of the family member in HC and the strengthening of the family support network, in order to provide more resolute coping strategies, both for the caregiver and for the individual with PI who receives care, this article aims to analyze the experience of family members in the home care of people with PI.

METHODS

This is descriptive research with a qualitative field approach which aims to describe and decode the components of a complex system of meanings through the researcher, by integrating the agents involved and allowing the exploration of the particularities of the interviewees, according to human experience, neither measurable nor quantifiable.⁽¹⁴⁻¹⁵⁾

The research was carried out in the municipality of Vitória da Conquista, in the state of Bahia, which has 370,879 inhabitants⁽¹⁶⁾, and 29 Primary Care Health Units⁽¹⁷⁾. The collection was carried out in two Primary Care services with HC, which are a Basic Health Unit and a Family Health Unit. The interviews were directed to informal family caregivers, who received the support of health professionals from the HC service of these units, such as home visits of physicians and nurses, support in the treatment of wounds and specialized services in the care of the older adults from April to May 2023.

The inclusion criteria of the subjects in the research were: family members who received support from the HC service and who were the main informal caregivers of people with PI from stage 3 onwards. This minimum criterion of PI was established because, from this stage of the injury, there is a need for more accurate care, considering, therefore, more challenging for the caregivers. Family caregivers who had professional training in the health area, and those who had some cognitive, auditory and/or communication deficit were excluded.

For the study, 13 subjects were selected randomly, non-probabilistically and for convenience. However, 2 were excluded from the sample, as they revealed that they were formal caregivers and had cognitive deficits. The final sample totaled 11 family caregivers. The collection was terminated from the saturation of data, when there was repetition of categories and speeches, without the emergence of new subjects.⁽¹⁸⁾

A semi-structured interview was conducted and a questionnaire was applied to identify the profile of family members working in care, as well as the degree of kinship, time of exercise in the function of main caregiver, age and sex. A Community Health Agent accompanied the interviewer to the residence where the research was carried out, and the interview was conducted in a private space using an audio recorder. The stimulus for narration was: tell me about your experience in the the home care of your family member with PI? Subsequently, the content was faithfully transcribed, the speeches were grouped and analyzed.

The analysis of the data followed the thematic content analysis of Bardin (1977), which unfolds in three moments: pre-analysis, which consisted of floating reading, constitution of the corpus and reformulation of hypotheses and objectives; exploration of the material, a classificatory operation that aimed to achieve the understanding of the text in the direction of categories; and, treatment of the interpreted results, which involved the organization of the information obtained.⁽¹⁹⁾

The research was developed in accordance with Resolution 466 of December 12, 2012, approved by the Permanent Education Pole of Vitória da Conquista and by the Human Research Ethics Committee of the Institute of Health Sciences of the Federal University of Bahia (opinion number: 5,937,167 and CAAE:

66914023.1.0000.5556), with the consent of the participants signed through the Informed Consent Form – ICF.

RESULTS

Of the 11 family caregivers interviewed, 10 were female, with a mean age of 47 years, ranging from 25 to 67 years, 5 were married, 4 single and 2 divorced. The mean time they cared for the family member with PI was 7 years and in relation to the degree of kinship, most were children (n=09), the others reported being daughter-in-law (n=01), grandson (n=01) and nephew (n=01).

The analysis of the statements about the experience of family members in the care of people with PI allowed the classification of the results into four categories: 1) Performance of family members in the care of PI; 2) Support of the HC service to the family and the patient with PI; 3) Overload of family caregivers; 4) Satisfaction in repaying the care received.

Category 1: Performance of family members in the care of PI

This category presents some statements from caregivers about knowledge and practices for performing PI dressings. It was found that, for the performance in wound care, family members are mainly based on the guidance provided by HC health professionals.

“[...] So I clean it, I leave it very clean, the good that doesn't stink and nothing; then it gets easier, see? [...] Then I come with the ointment, I pass only inside the wound, the physician said that it was not good to go through the edges, then I do not pass, only inside, then I take the gauze and close it with the adhesive and put her diaper after [...]” (Oliveira)

“[...] I clean it first, right; with this rag here... what do you call it? Gauze, right? So, then I take the saline solution that is in the refrigerator and clean everything there, then I put the sunflower oil on the wound and on her whole body because they say it's good, right? [...]” (Seringueira)

In the following statements, it is possible to notice the insecurity that caregivers have to provide care for the wound, without having the guarantee that the technique they use to perform the dressing will bring improvement to the patient.

“[...]I take care of his wound the way I know, but it doesn't work, and sometimes I even prefer him to stay more days in the hospital just for the people there to take better care of him[...]” (Jacarandá)

“[...]But I take care of him and my fear is to get worse. [...] because then, I take care of the way I know. What if he gets better? I don't know, but he won't be worse than he already is. You know? [...]” (Quaresmeira)

Category 2: Support from the HC service to the family and the patient with PI

Most of the interviewees reported that the HC service provides the materials for dressing, and that health professionals follow up at home.

“[...]The post here is very good, the physician comes at least once a month here and the nurse too, they give me everything, sometimes I go there to get when there is a lack of medications, the dressing things they also bring or I go there to get [...] Everything I need here they give me, then it's good [...]” (Oliveira)

However, some statements portrayed the precariousness in the service in relation to professional monitoring and the supply of materials, leaving it up to the family to often seek such resources and sometimes encounter financial difficulties.

“[...]The staff at the clinic used to come and take care of the patient, but then they didn't take care of him anymore and I was left taking care of the patient in my own way, you know? [...]The clinic gives me material to change the dressings, sometimes it does and other times it doesn't [...]I think they have to give me things, since they no longer come to do the dressing; So at least the material I have to have, do you agree? [...]” (Ipê)

"[...]They help me, they give me materials when they run out, but I still have to buy things and it's not cheap, you know? [...] so my mother's retirement salary has to be used for food, for some medications, which sometimes the health center doesn't provide and for the dressing supplies [...]" (Quaresmeira)

Category 3: Overload of family caregivers

It was clear in the speech of all family members, the overload both physical and emotional that the care the person with PI generates. Many reported loneliness, as there was no involvement of other family members to share the care, which showed a predisposition to change in the social and emotional well-being of the caregiver.

"[...] so I don't think I'm obliged to carry this burden alone again, my brothers should also help me. I just want to be at peace or for my brothers to help me [...] I'm tired. I'm exhausted [...]" (Jacarandá)

"[...] I do it alone, but often only I take care of it, I spend twenty-four hours with her and I don't have time for myself anymore. There are days when I just want to be quiet in my corner, because I get too tired [...] but I get tired more mentally than physically [...] I can't go there at the post to go through the nurse to do an exam that I always do, because I have no one to leave her with [...] I need to go to the dentist, I can't because I won't leave her alone[...]" (Copaíba)

Category 4: Satisfaction in repaying the care received

The profile of the family caregivers in this study are people who, for the most part, have the degree of kinship of a child, because of this, many have a very strong feeling of gratitude, and even for those who have another type of kinship, they see in care the opportunity to repay the love received, despite all the physical and mental fatigue reported in the interviews.

"[...] I feel so tired while taking care of her, but at the end of the day I'm fine. My spine hurts, right? Age comes to everyone and so does back pain. But sometimes I think I could do more for my mother, she's my love, you know? I do what I can[...]" (Quaresmeira)

"[...]She was the one who raised me, so she is the mother I didn't have, right, so I have a lot of patience to take care of her, because there are a lot of people in this world who do things grudgingly, and I don't [...]" (Seringueira)

"[...]As a daughter-in-law, I took on this responsibility of taking care of her, I love her too much and consider her as a mother, so everything I need to do to try to give her the best I go there and do [...]" (Juazeiro)

DISCUSSION

Home care represents a possibility of care for the person with PI beyond the hospital scope and results in the reduction of numerous risks for the patient, in addition to providing physical and emotional comfort. In this context, the family becomes an important element for home care to be effective,⁽²⁰⁾ as also evidenced by this research.

However, as observed in the results of this study, the literature provides evidence of the difficulties experienced by family members to perform this care, such as: financial and physical overload; lack of preparation of the caregiver to deal with PI; lack of support from health professionals; family conflicts; and, finally, the concentration of the responsibility of care in a single person.⁽¹²⁾

The role of caregiver is mostly performed by women, which can also be observed in this research. The feminization of care management can be explained by the historical and cultural context that permeates society, by directing and associating care to the female figure. Sometimes, women, due to the invisibility of their work at home, need to take care of their family members who have a health problem.⁽²¹⁾

It is notorious, and research points out, that women have a higher percentage of home care, as they are responsible for both domestic work and the provision of care to the sick family member, which causes physical and emotional overload due to the multiple tasks assumed ⁽²³⁾. This accumulation of attributions

is perceived in different ways by these women caregivers who, despite considering themselves responsible for these functions, refer to loneliness and overload.⁽²⁴⁾

Many family members, in the care of PI, use popular or acquired knowledge with experience over the years. This generates insecurities in the conduct and in the reflection of this care in the recovery of the wound ⁽⁶⁾. In this sense, the support provided by health professionals during the home visit exerts a strong influence on the direction of care and promotes safety to the family in the management of injuries.⁽²⁵⁾

Based on this assumption, nursing has traditionally been the field in which several strategies are applied to promote patient safety, as it is closely related to health promotion. Therefore, it is up to the nurses to initiate home care guidelines for family members, clarifying doubts and guiding what should be done during wound care.⁽²⁶⁾

The family member who plays the role of informal caregiver, most of the time, does not have a technical-professional preparation to provide care to the person with PI. In addition, some have limitations that are not limited to a lack of technical knowledge, but include the lack of financial support, emotional skills and the presence of a family support network sufficient to provide care.⁽²⁾

For some family caregivers, socioeconomic vulnerability is a reality, as many need to give up their paid jobs to take care, a reality that was not only found in this research. Many informal caregivers suffer financial difficulties because they have to assume some expenses related to the treatment of the sick family member, in this sense, it is necessary to support the health services in providing sufficient materials to carry out the care.⁽²⁷⁾

The overload generated by loneliness in the performance of care is another very common reality among family caregivers, where the commitment turns out to be of only one family member, either because they feel obligated or due to need or lack of option,⁽²⁸⁾ which was also verified in this study. By taking responsibility for the care of the loved one, the caregiver's routine is completely changed to include activities that require dedication, sometimes integral.⁽²⁹⁾

In this sense, exercising the role of caregiver brings with it some disorders and emotionally delicate situations, such as those described by the interviewees and evidenced in some studies.^(3,9) First, there are emotional conflicts and high physical demand due to the act of caring for the other person.⁽⁹⁾ Thus, it is common for caregivers to isolate themselves socially, consequently presenting deficits in physical health and self-care, in addition to the possibility of developing depression, joint pain, financial difficulties and aggravation of pre-existing diseases.⁽³⁾

However, a study shows that, despite the difficulties faced by caregivers, there is a feeling of gratitude, affection and the desire to help and provide better comfort to the sick family member, which helps to alleviate the stress that involves care in the home environment ⁽³⁾. This corroborates other studies that show that motivation, generated by the caregiver's affection and love for the family member, is greater than dissatisfaction and exhaustion related to care ⁽³¹⁾. A finding that also appeared in this research, where many reported, in the performance of care, contradictory feelings of stress and satisfaction.⁽³²⁾

The limitations presented by this study may be related to the experiences of family caregivers from only one geographic location, therefore, there is a need for further studies that can explore the theme in the reality of other regions. This research contributes to rethinking care strategies in HC services, focusing not only on the patient, but on the caregiver.

CONCLUSION

In general, the difficulties faced by family members in the home care of patients with PI are multifaceted and cover different aspects. First, the lack of knowledge of the dressing technique can be a significant challenge, and the lack of adequate guidance and training can hinder the ability of family members to provide the necessary care.

The burden faced by family members, especially women, to take care of these people with PI is a challenging reality, since the continuous care and the associated responsibility proved to be physically and emotionally demanding.

It was found that the feeling of contributing to the care of the loved one can bring great personal satisfaction and a sense of purpose, as well as the strengthening of the emotional bond between family members, creating even deeper bonds of love and care.

The experiences brought by the family members reveal the importance of a more attentive and sensitive follow-up to the needs of the caregivers, based on a reflection of the professionals of the HC

service on their practices, in order to guarantee adequate physical and emotional resources for the care, not only of the PI patients, but their families.

CONTRIBUTIONS

Contributed to the conception or design of the study/research: Gomes, LS; Cunha, JPX. Contributed to data collection: Gomes, LS. Contributed to the analysis and/or interpretation of data: Gomes, LS; Cunha, JPX. Contributed to article writing or critical review: Kochergin, CN; Santos, RS. Final approval of the version to be published: Gomes, LS; Cunha, JPX; Kochergin, CN; Santos.

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