

# PERCEPTIONS AND EXPERIENCES OF FAMILY CAREGIVERS OF BEDRIDDEN ELDERLY

*Percepções e vivências de cuidadores familiares de idosos acamados*

*Percepciones y vivencias de cuidadores familiares de mayores encamados*

Original Article

## ABSTRACT

**Objective:** To know the perceptions and experiences of family caregivers of bedridden elderly. **Methods:** A qualitative descriptive exploratory study conducted in January 2015 with four caregivers in a Family Health Center in the municipality of Araripe, CE. Data were collected through semi-structured interviews and the information was organized using the content analysis technique. A total of three categories emerged from the analysis of the reports of caregivers: the dependence process of the elderly; daily difficulties experienced by the caregiver; and satisfaction with the home care service. **Results:** The dependence process of the elderly took place as a consequence of pathological processes such as neoplasm, cerebrovascular accident and dementia. However, it could also be observed that physiological phenomena – common in old age – can also make individuals dependent on caregivers. As to the difficulties faced by the caregivers, they reported the need for greater involvement by the family, given that the centralization of work generates an overload and hence affects the care of the elderly. Teamwork in the home care context is fundamental, given that it allows a complementary and comprehensive care to the elderly/caregiver binomial. **Conclusion:** Healthy aging is a major challenge to be overcome given that the development of a healthy lifestyle is difficult in all social strata. It is necessary to improve home care in order to provide support to caregivers so that the quality of life of bedridden elderly and caregivers is improved.

**Descriptors:** Caregivers; Elderly; Family; Frail Elderly.

## RESUMO

**Objetivo:** Conhecer as percepções e vivências de cuidadores familiares de idosos acamados. **Métodos:** Estudo descritivo, exploratório, com abordagem qualitativa, realizado em janeiro de 2015 com quatro cuidadores em uma Unidade de Saúde da Família no município de Araripe-CE. A coleta de dados deu-se a partir de uma entrevista semiestruturada, sendo as informações organizadas através da técnica de análise de conteúdo. A partir da análise dos depoimentos dos cuidadores, emergiram três categorias: o processo de dependência do idoso; dificuldades vivenciadas no cotidiano do cuidador; e satisfação com o serviço de saúde no domicílio. **Resultados:** O processo de dependência do idoso ocorreu como consequência de processos patológicos, como neoplasia, acidente vascular encefálico e demência. No entanto, notou-se também que os fenômenos fisiológicos, próprios da velhice, também podem levar o indivíduo a tornar-se dependente dos cuidadores. Quanto às dificuldades enfrentadas pelos cuidadores, estes relataram ausência de envolvimento maior da família, haja vista que a centralização do trabalho gera sobrecarga e, conseqüentemente, afeta o cuidado com o idoso. O trabalho em equipe no contexto domiciliar é fundamental, pois permite um atendimento complementar e integral para o binômio idoso/cuidador. **Conclusão:** Envelhecer de forma saudável é o grande desafio a ser superado, pois o estabelecimento de hábitos de vida saudáveis é uma dificuldade vivenciada por todos os seguimentos sociais. Faz-se cada vez mais necessária a melhoria do atendimento domiciliar, com vistas à prestação de suporte aos cuidadores com vistas à melhor qualidade de vida do idoso acamado, bem como do cuidador.

**Descritores:** Cuidadores; Idoso; Família; Idoso Fragilizado.

## RESUMEN

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**Objetivo:** Conocer las percepciones y vivencias de cuidadores familiares de mayores encamados. **Métodos:** Estudio descriptivo, exploratorio de abordaje cuantitativo realizado en enero de 2015 con cuatro cuidadores de una Unidad de Salud de la Familia del municipio de Araripe-CE. La recogida de datos se dio a partir de una entrevista semiestructurada y las informaciones fueron organizadas a través de la técnica del Análisis de Contenido. A partir del análisis de los relatos de los cuidadores emergieron tres categorías: el proceso de dependencia del mayor; las dificultades vivenciadas en el cotidiano del cuidador; y la satisfacción con el servicio de salud del domicilio. **Resultados:** El proceso de dependencia del mayor se dio como consecuencia de procesos patológicos como la neoplasia, el accidente vascular encefálico y la demencia. Sin embargo, se notó también que los fenómenos fisiológicos, propios de la vejez, también pueden llevar al individuo a depender de los cuidadores. Sobre las dificultades afrontadas por los cuidadores los mismos relataron la ausencia de mayor involucramiento de parte de la familia ya que la centralización del trabajo genera sobrecarga y, en consecuencia, afecta el cuidado con el mayor. El trabajo del equipo en el contexto domiciliario es fundamental pues permite una atención complementaria e integral del binomio mayor/cuidador. **Conclusión:** Envejecer de manera saludable es el gran desafío a superar pues el establecimiento de hábitos de vida saludables es una dificultad vivenciada por todos los seguimientos sociales. Se hace necesario cada vez más la mejoría de la atención domiciliar para la prestación del apoyo a los cuidadores para una mejor calidad de vida del mayor encamado así como del cuidador.

**Descriptor:** Cuidadores; Anciano; Familia; Anciano Frágil.

## INTRODUCTION

Aging is a natural and chronological process that encompasses all individuals; however, the chronological age cannot be a determining factor to identify older people<sup>(1)</sup>. In the senility process, the body undergoes natural modifications<sup>(2)</sup>.

According to the *Instituto Brasileiro de Geografia e Estatística - IBGE* (Brazilian Institute of Geography and Statistics), Brazil has 14.9 million older people that account for 7.4% of the total population. It is estimated that by 2060, the population of older people will comprise 58.4 million individuals. During this period, the average life expectancy of Brazilians may increase from the current 75 years to 81 years<sup>(3)</sup>.

Each individual ages in a single way that is influenced by external, genetic and lifestyle factors. There are two predominant factors that act on aging: intrinsic factors that act from the inside of the person, described as normal aging; and extrinsic factors, which are the physical agents (temperature, radiation, humidity, power, chemicals) and infectious agents (viruses, fungi, bacteria, protozoa)<sup>(4)</sup>.

Aging constitutes a social advance and longevity is apparent in modern times. However, it also constitutes a public health problem, as these people need specialized care and support because of the greater likelihood of developing diseases due to advancing age and anatomical and physiological changes that can lead to dependence<sup>(5)</sup>.

The changes resulting from this process can affect the entire body, but some systems are more susceptible to complications, such as the cardiovascular system, the nervous system, the musculoskeletal system, and the endocrine system. Changes towards chronic conditions can lead to a loss of autonomy, dependence, and social and emotional changes in older people<sup>(6)</sup>.

Some common alterations in aging include sarcopenia (reduced muscle mass), osteopenia (reduced bone mass), reduced body water content, reduced aerobic capacity, among others. These alterations lead to an increased risk of accidents such as falls, which may lead older people to become bedridden; it also has effects such as the occurrence of pressure ulcers, respiratory and urinary tract infections, among others<sup>(6)</sup>.

According to the Federal Constitution of 1988, the older person is seen as an individual in need of protection and care, and the family, the society and the State have the duty to cherish them and give them support for conviviality and well-being in the community<sup>(7)</sup>.

The role of caring for older people is sometimes taken abruptly by a family member, particularly women<sup>(8)</sup>. Becoming a caregiver is something that requires attention, responsibility, patience and love for the others. However, among these requirements, basic support is necessary to meet the needs of older people; still, this support is sometimes missing, and the family becomes responsible for caring for bedridden older people even without the technical knowledge necessary to do so.

The present study focused on the experience of caregivers of bedridden older people, highlighting the problems faced in the home environment as well as the difficulties arising from the lack of support from the primary care system and the role of social support. In this context, the following question arose: how do family caregivers of bedridden older people perceive and experience the process of caring for them?

Thus, the study aimed to know the perceptions and experiences of family caregivers of bedridden older people.

## METHODS

This is a qualitative descriptive and exploratory study.

In qualitative research, knowledge originates from information from people directly linked to the experience

studied; therefore, they cannot be controlled and generalized. The data, in turn, are not isolated things, fixed events, or pure and defined perceptions, that is, all events within a context are equally important, including the consistency of the manifestations, their occasionality, the frequency, the interruption, the speech and the silence<sup>(9)</sup>.

In turn, the exploratory research allows adding experiences about the nature of the subject or phenomenon through engagement with the subject studied. Therefore, the exploratory research is the one that explores something new, which is often not considered science but is the basis of science. According to some authors, the exploratory research does not work out hypotheses and is used when there are few scientific studies and little knowledge on the subject<sup>(10)</sup>.

On the other hand, the descriptive research is conducted from the reports made by the study subjects. The descriptive research aim to describe the characteristics of a given population or establish analogies between variables<sup>(11)</sup>.

The research took place in January 2015 in the municipality of Araripe, Ceará, located in the microregion of the Chapada do Araripe, which is 526.8 km far from the capital city Fortaleza. It has an estimated population of 21,214 inhabitants<sup>(12)</sup>.

Currently, the municipality of Araripe has eight *Unidades de Saúde da Família - USF* (Family Health Centers) and eight *Equipes de Saúde da Família - ESF* (Family Health Teams), three in urban areas and five in rural areas, offering the following services: patient embracement and medical, dental and nursing services. The facilities develop health promotion, protection and recovery actions. The secondary health network of Araripe also has a small hospital that provides the four basic clinical services (medical, surgical, obstetrical and pediatric). In addition, it has one *Centro de Atenção Psicossocial - CAPS* (Psychosocial Care Center) and one *Centro de Especialidades Odontológicas - CEO* (Dental Specialties Center).

The research was conducted in a USF located in the urban area of the municipality of Araripe. According to data from the *Sistema de Informação da Atenção Básica - SIAB* (Primary Care Information System), the health facility currently has a registered population of 3,005 people; of these, 322 are older people, who correspond to 11% of the total<sup>(13)</sup>. Such health center has a total of six bedridden older people who receive care from a family member.

The research universe comprised six family caregivers of older people admitted to the aforementioned health center; however, there were two refusals. Thus, the sample consisted of four caregivers. The inclusion of participants obeyed the following criteria: a) being the main

caregiver of dependent older people; b) having a first or second degree of kinship; c) living with the older people; d) having the cognitive capacity to respond to the interview.

During the research, the “data saturation” criterion was used because in qualitative research the numerical criterion is not a priority and there is no concern with generalization<sup>(9)</sup>.

Data were collected using a semi-structured interview guide. Sociodemographic characteristics of caregivers were addressed: name, age, gender, marital status, education, religion, occupation and degree of kinship; data related to the older patient were also assessed: age, gender, marital status and the underlying disease associated with dependence and bedridden condition. The guiding question for the caregiver was: how do you experience caring for a bedridden older person?

The semi-structured interview guide should unfold the various indicators considered essential and sufficient in topics that include the scope of the expected information. Topics should work just like reminders and should, as far as possible, be memorized by the investigator when s/he is on the field. Serving as a guide to the progress of the dialogue, the interview guide must be constructed so as to allow flexibility in conversations<sup>(14)</sup>.

In order to facilitate the collection of information, a digital recorder was used to reproduce the full speech of research subjects in order to avoid the risk of misinterpretation. This feature allows the researcher to stay tuned to the speech of the interviewee<sup>(9)</sup>.

The organization of data was performed using the content analysis method. The process of content analysis can be divided into three stages: pre-analysis, exploration of results and interpretation of information<sup>(15)</sup>. The pre-analysis is the organization of the work itself. It is the stage in which the researcher chooses the study object and formulates the objectives of the work. After deciding what to study, it is necessary to establish the corpus of the study. The corpus is nothing more than the whole material subjected to analysis. The exploration of the material is a long stage that includes coding or enumeration procedures on the basis of pre-formulated rules.

Simple or complex statistics allows us to establish an overview of results based on tables or diagrams that condense the information provided for analysis. The last stage of the content analysis process is the interpretation of results, which means literally interpreting the results found. For this, it is necessary to focus carefully on the theoretical frameworks relevant to the research, as they allow the foundations within the perspectives that are meaningful to the study and hence support the findings<sup>(15)</sup>.

In all, three thematic categories emerged from analysis of the speech of caregivers: the dependence process of the

older person; daily difficulties experienced by the caregiver; and satisfaction with the home care service.

Because it is a research with people, all the ethical guidelines were followed according to Resolution 466/2012 (Guidelines and Norms Regulating Research involving Human beings) of the *Conselho Nacional de Saúde - CNS/MS* (National Health Council)<sup>(16)</sup>.

This study was approved by the Research Ethics Committee of the Federal University of Ceará under Opinion No. 660.902 and CAAE No. 24721914.8.0000.5054. The caregivers interviewed signed a Free Informed Consent Form prior to the interview. To guarantee anonymity, respondents were identified as: I1, I2, I3 and I4.

## RESULTS AND DISCUSSION

Sociodemographic data of respondents and the information on the older patients are presented below followed by the themes that emerged from the study.

The research was conducted with four female caregivers aged 41-72 years who were first degree relatives. Regarding education, three were uneducated and one had attended elementary school.

Similarly, a study that identified the profile of family caregivers of patients with sequelae of cerebrovascular accident (CVA) also showed that the majority of respondents were female<sup>(17)</sup>.

Regarding the degree of kinship, the literature points out that the role of caregiver is shifted to the children when the spouse is deceased or cannot take this role. In this case, the care is permeated by a moral obligation originated from values imposed by the family culture, which believes that children should care for their parents as a payback for the care provided during their childhood and adolescence<sup>(18)</sup>.

With regard to education, the data found in the present study are in agreement with another study conducted with family caregivers of older people, according to which most of the participants had studied from one to four years and few were illiterate<sup>(19)</sup>.

Regarding marital status, two respondents were married and the other two were widowed; however, the four caregivers had children. As for religion, all declared themselves Catholic. Three of the respondents were agriculture workers and one was a maid. The period of time caring for the person since the onset of dependence ranged from two to eight years.

The age of the older patients ranged 73-92 years. As for gender, three were women and one was a man. Regarding marital status, two were married and the other two were widowed. The underlying diseases associated

with dependence and bedridden condition were: urinary and fecal incontinence, dementia, stroke and cancer.

### The dependence process of the older person

The dependence process of the older person, according to the participants, shows that it was predominantly caused by pathological processes. Only one respondent reported that the older patient's dependence was associated with a physiological process. The following statements refute this information:

*"He started to feel painful urination [...] so we came to the doctor [...] he said he had to undergo an operation [...] it's been six years since he became dependent on me." (I1)*

*"She went to bed at night, then she woke up talking [...] she had that problem, a stroke! So we took her to the hospital, they gave her some medicines [...] she faltered, her joints got stiff [...] she also had rheumatism!" (I2)*

*"[...] it's been six years now, her body was weakening [...] now she's being fed through a tube, she can't even eat. The doctor says that she has no disease, that this is because of her weakness, because of age, and he doesn't know why she got like this, because she has never undergone any surgeries, nothing." (I4)*

It was noted that the process of dependence and the consequent bedridden condition occurred as a result of pathological processes already mentioned, such as cancer, stroke and dementia. However, it was also noted that the physiological phenomena that are common in old age can also lead the individual to become dependent on someone else's care.

The stroke is conceptualized as a clinical sign of rapid development of focal disturbance of cerebral function supposedly of vascular origin lasting more than 24 hours. It has a high incidence among older people. Every year, 15 million people worldwide suffer a stroke; of these, five million die and another five million are disabled to some degree, generating functional incapacity<sup>(20)</sup>.

The importance of the ESF in assessing the history of the older patient should be highlighted, as it enables a better understanding of the factors associated with dependence, indicates measures that can be taken to prevent possible injuries arising from dependence and supports the analysis of the evolution of the health status of the older patient.

Faced with the dependence, the family caregiver becomes primarily responsible for the older person – not by choice, but generally as an obligation, as the following testimonials expose:

*“Because there was no one to take care of them, so it had to be me [...] I was the only daughter that could do that. The other daughter didn’t want to take care of them, she said she couldn’t. I wouldn’t cast them aside, so I had to take care of them [...]. The others would do it this way: they got there, cooked lunch, and then left [...] so, two clients like these can’t be at home without someone to help. There is the medication time, the food time, the shower time, so that was the reason I came here.” (11)*

*“I feel attached to her, because we have to take care of her. There are medications, showers... but I don’t think that taking care of her is bad. I like it, because she’s my mother, I do it with pleasure.” (13)*

*“I feel tired, because she depends on everything, and I also have a problem in the back. It gets harder for me to take care of her properly.” (14)*

It was observed that the caregiver’s role is taken by the daughter, that is, a first-degree relative who experiences many difficulties, particularly the unavailability of other family members to assist in carrying out the tasks associated with the care of the older patient, a fact that causes work overload, which reflects negatively on their quality of life.

On the other hand, the sense of obligation gives rise to affection as the care is surrounded by a feeling of love and retribution<sup>(18)</sup>.

Historically, the woman has always been responsible for the care of either the house or the children, while the man’s role was to work outside the home to ensure the financial provision of the family. And despite all the social and family composition changes and the new roles taken by women, especially their greater participation in the labor market, they are still expected to perform this function<sup>(21)</sup>.

It is the role of the health team to sensitize the family about the importance of sharing tasks to ease the burden of activities and establish a responsibility relationship between family members regarding the care of the older patient.

### **Daily difficulties experienced by the caregiver**

The category “daily difficulties experienced by the caregiver” shows that the problems are related to the performance of daily care, such as personal hygiene, feeding and changing positions, according to the following statements:

*“So, we have to get up very early to bathe him [...] He doesn’t wear diapers, he wears only shorts. I have to put the food in his mouth [...]. It is very difficult [...]. Say, it is difficult because I can’t lift him up all by myself, but I have to [...]. See how many sheets I have already washed. I have already washed about twenty sheets today because of urine.” (11)*

*“Dude, as long as she’s quiet, it is fine. Now, the worst*

*moment is the bath time because I can’t do it alone [...]. I need someone else because she is heavy and I can’t lift her up alone and move her to the chair and then bathe.” (13)*

According to the testimonials, the personal hygiene of the older patients, especially the bath, is the main difficulty experienced by the caregiver. This is due to the locomotion impairment of the patient, which requires that the caregiver uses a greater physical strength to carry this individual from one environment to another as well as to change positions in bed. In addition, there is no one to assist in carrying out these tasks, which ends up overloading the caregiver, who is often too old, and hinders even more the process of care.

Family caregivers are those that meet self-care needs of people with some degree of dependence, such as food and hygiene. This role is, in most cases, taken by women, daughters or wives living with the older patient and who care for him full time; additionally, it is almost always a solitary activity done without the help from other family members<sup>(22)</sup>.

The same study showed that caregiver’s work overload is directly related to psycho-emotional disorders, the amount of time spent on caring, the caregiver’s lack of information, the degree of dependence of the older patient, the presence of depression and incontinence<sup>(22)</sup>.

Given the difficulties experienced by caregivers, it is clear the importance of the ESF and the *Núcleo de Apoio à Saúde da Família - NASF* (Family Health Support Center) in providing the caregiver with emotional support through home visits, therapeutic listening and/or groups for sharing experiences. Moreover, the focus of these professionals should include efforts for the acquisition of autonomy and independence by the older patient to improve self-care<sup>(23)</sup>.

### **Satisfaction with the home care service**

This category refers to the assistance provided by the ESF in the household according to the following reports:

*“[...] so, on the day of the visit [...], they come and get the device and check dad’s blood pressure [...] I ask them to tell when they come because sometimes they come and I am doing the laundry.” (11)*

*“I like it, oh my God!! Because sometimes we feel pain, dizzy, so they come here. We call and the medicine is rapidly delivered. When they see it won’t work, they tell us to go to hospital.” (12)*

*“It’s nice because there are the days they come here. You know, it’s only once a month [...]. If they came every week [...], but they can’t [...]. But we get happy this way, because they are always watching over us and checking how he is.” (13)*

*“It is good because they always give us strength; they*

*come here and see [...]. When we need, they take us to hospital and do everything.” (14)*

It became clear that the home visits are highly regarded by the interviewees, as they promote the establishment of a link with the community that makes the assistance more effective and improves its problem-solving capacity.

Given that older people in fragile or more vulnerable conditions do not attend health services very often, the type of home care should be planned by the ESF to ensure the link with the health system<sup>(24)</sup>.

The home care provided by the ESF focuses on counseling actions regarding drug treatment, personal and food hygiene; in addition, the ESF also performs basic procedures such as blood pressure measurement, as the following quotes expose:

*“They tell me to give his medication, they ask about the medications he takes. If we are out of any medications, I tell them. If they have it in the health facility, they give us. And if they don't have it, they give me the prescription for me to buy.” (11)*

*“[...] they measure her blood pressure and say she's healthy because she has no hear problems. They just keep talking about her boné, because sometimes they are stiff, the legs won't move [...].” (12)*

*“To be careful with the tube and always take care of hygiene, food, we can't neglect anything. They come and measure the blood pressure, they come and listen to you carefully.” (13)*

It was found that the work done by health teams at home is focused on providing information related mainly to food and proper use of medications, which are fundamental for health promotion and disease prevention, such as iatrogenic complications, which are common at this stage of life due to continuous use of medication.

In fact, home visits are a privileged opportunity for contact and development of educational activities with family and other significant people, which are the social support to users and contribute to the maintenance of healthy habits<sup>(25)</sup>.

## FINAL CONSIDERATIONS

The study highlighted three important aspects: the causes associated with the dependence of the older patient; the main problems experienced in the daily lives of caregivers; and the satisfaction with the health service.

The dependence process and the consequent bedridden condition occurred as a result of pathological processes such as cancer, stroke and dementia. However, it was also

noted that physiological phenomena that are common in old age can also lead the individual to become dependent on caregivers.

Regarding the problems faced by the caregiver, there is the need for greater involvement of the family as for the division of tasks, as the centralization of work generates an overload and decreases the caregiver's quality of life, which, consequently, affects the care of the older person.

The satisfaction with the health service relates directly to the bond that is established between the health service and family in the home environment. The teamwork in the home context is crucial because it allows a complementary and comprehensive care to the older person/caregiver binomial.

In this perspective, greater investment should be made in home care, such as the expansion of the *Serviço de Atendimento Domiciliar - SAD* (Home Care Service), as it allows a complementary and comprehensive care provided by a multidisciplinary team that works both for disease prevention and for health promotion of bedridden patients at home.

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