



## FAMILY MEMBERS'/CAREGIVERS' PERCEPTIONS ABOUT DOMICILIARY HOSPITALIZATION OF PEOPLE DEPENDENT ON CARE

*Percepções de familiares/cuidadores sobre internação domiciliar de pessoas com dependência de cuidado*

*Percepciones de familiares/cuidadores sobre la internación domiciliar de personas dependientes de cuidado*

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### ABSTRACT

**Objective:** To analyze family members'/caregivers' perceptions about domiciliary hospitalization of people with chronic or terminal illnesses receiving care from health professionals. **Methods:** A qualitative study was conducted between March and April 2014 using semi-structured interviews held at the households of patients in domiciliary hospitalization with eight family members/caregivers in a municipality in Bahia, Brazil. The data were analyzed using the content analysis method, which allowed the identification of the study category – family member'/caregivers' perceptions about domiciliary hospitalization of people dependent on care. **Results:** The interviewees reported being satisfied with domiciliary hospitalization due to the differentiated care that is provided, the reduction in hospital trips, the comfort, and the interaction between the health team, family members and the person in need of care. In addition, care is provided based on respect for the individuality and singularity of each family. The interviewees also said that the number of professionals was not enough and there was a need to expand the team. Thus, the team should be made aware of the importance of discussing the rights of family members/caregivers as citizens. **Conclusion:** According to the interviewees' perceptions, domiciliary hospitalization is a modality of care that is complementary to essential hospitalization as the home care team provides humanized care and is close to the family. However, the interviews showed that the service offered to these patients seems to be a favor and not a right of the patient to get this public health service.

**Descriptors:** Perception; Home nursing; Family; Caregivers.

### RESUMO

**Objetivo:** Analisar as percepções de familiares/cuidadores sobre a internação domiciliar de pessoas com doenças crônicas ou em estado terminal na assistência prestada por profissionais de saúde. **Métodos:** Realizou-se um estudo qualitativo, entre



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março e abril de 2014, com entrevistas semiestruturadas, no domicílio de pacientes em internação domiciliar, com oito familiares/cuidadores em um município da Bahia, Brasil. Analisaram-se os dados pelo método da análise de conteúdo, que permitiu a apreensão da categoria do estudo – percepções dos familiares/cuidadores de pessoas com dependência de cuidado sobre a internação domiciliar. **Resultados:** Os entrevistados demonstraram satisfação com a internação domiciliar, pelo cuidado diferenciado desse modo de atenção, pela redução de deslocamentos e por proporcionar conforto e interação entre equipe de saúde, familiares e a pessoa que necessita de cuidados. Além disso, o cuidado é respaldado no respeito à individualidade e à singularidade de cada família. Também se viu que os entrevistados compreendem o quantitativo de profissionais como insuficiente, havendo necessidade de ampliar a equipe. Assim, convém sensibilizar a equipe sobre a relevância de discutir com familiares/cuidadores sobre seus direitos como cidadãos. **Conclusão:** O internamento domiciliar, na percepção dos entrevistados, é uma modalidade complementar à hospitalização essencial, uma vez que a equipe domiciliar proporciona um cuidado humanizado e próximo à família. Contudo falas evidenciam que o serviço ofertado a esses pacientes parece ser um favor prestado a eles, e não um direito do paciente de receber esse serviço público de saúde.

**Descritores:** Percepção; Assistência Domiciliar; Família; Cuidadores.

## RESUMEN

**Objetivo:** Analizar las percepciones de familiares/cuidadores sobre la internación domiciliar de personas con enfermedades crónicas o en fase terminal para la asistencia de profesionales sanitarios. **Métodos:** Se ha realizado un estudio cualitativo entre marzo y abril de 2014 con entrevistas semiestruturadas en el domicilio de pacientes de internación domiciliar con ocho familiares/cuidadores de un municipio de Bahía, Brasil. Se analizaron los datos por el método de análisis de contenido que ha permitido la aprensión de la categoría del estudio – percepciones de los familiares/cuidadores de personas dependientes de cuidado sobre la internación domiciliar. **Resultados:** Los entrevistados demostraron satisfacción con la internación domiciliar por el cuidado de ese modo de atención, por la reducción de desplazamientos y por el confort e interacción entre el equipo de salud, los familiares y la persona que necesita de cuidados. Además, el cuidado está respaldado en el respecto a la individualidad y la singularidad de cada familia. Se ha visto también que los entrevistados perciben el cuantitativo de profesionales como insuficiente y la necesidad de ampliar el equipo. Así, es oportuno da sensibilización del equipo sobre la relevancia de discutir con los familiares/cuidadores sobre sus derechos como ciudadanos. **Conclusión:** En la percepción de los entrevistados la internación domiciliar es una modalidad complementaria de la hospitalización esencial una vez que el equipo domiciliario proporciona el cuidado humanizado y cerca de la familia. Sin embargo, algunas hablas han evidenciado que el servicio ofrecido a esos pacientes se parece a un favor y no al derecho que tienen de recibir ese tipo de servicio público de salud.

**Descritores:** Percepción; Atención Domiciliar de Salud; Familia; Cuidadores.

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## INTRODUCTION

Domiciliary hospitalization (DH) within the Unified Health System (*Sistema Único de Saúde - SUS*) is a strategy consisting of home care provision to reduce the length of hospital stay by valuing innovations in spaces and forms of technology organization<sup>(1)</sup>. This kind of service allows for the provision of humanized care, expands access to care for people who need hospitalization, and directly influences the daily lives of family members<sup>(2)</sup>.

Home care refers to millenary practices of family health care, but the first initiatives of public regulation of this form of care occurred in the United States in the 1940s with the aim of freeing up hospital beds<sup>(3)</sup>. In Brazil, the first experience of home care dates to the late 1940s. Since then, different initiatives have been carried out due to the need to offer health services more compatible with the demographic and epidemiological transition processes, which are characterized by the population aging and an increase in chronic and degenerative diseases, and the need to create alternatives to reduce the costs of hospitalizations<sup>(4)</sup>.

Population aging is a major issue worldwide and international organizations estimate that by 2025 there will be 1.2 billion people over the age of 60 and the oldest-old (80+) will make up a large group of utmost importance<sup>(5)</sup> that will contribute to the increase in chronic diseases.

Chronic diseases are multifactorial and insidious and compromise the quality of life of individuals. Moreover, cardiovascular diseases, cancers, chronic respiratory diseases and diabetes mellitus are the main non-communicable diseases (NCDs)<sup>(6)</sup>. In 2012, 38 million deaths worldwide were caused by NCDs and nearly ¾ of them occurred in low- and middle-income countries<sup>(6)</sup>. From 2000 to 2011, NCDs accounted for 72.7% of total deaths in Brazil<sup>(7)</sup>.

Within this context, the Ministry of Health instituted the Domiciliary Hospitalization Policy through Ordinance No. 825, of April 25, 2016, which advocates for the reduction of the demand for hospital care or of the length of hospitalization with a view to promoting a more humanized care to improve the autonomy of users in their health care<sup>(8)</sup>.

Home care employs a set of different strategies and is one of the alternatives for the reorientation of health care practice. Additionally, it is in line with the National Health Promotion Policy whose focus of attention is the transversal promotion of health care in the Health Care Network through the promotion of humanized care practices based on the local needs and care comprehensiveness articulated with all health production equipment in the territory<sup>(9)</sup>.

Primary Health Care and Family Health Strategy teams are responsible for delivering home care, which is considered a follow-up of comprehensive health care that is closer to users' needs<sup>(10)</sup>.

Domiciliary hospitalization is a modality of care aimed at meeting the current needs of permanent care of people with chronic diseases or who are terminally ill. They help to avoiding hospitalizations, which make people more susceptible to acquire infections and distance them from the family environment<sup>(11)</sup>.

Home care is, therefore, an important alternative for the promotion of health and quality of life of people with limitations or dependent on care. In this context, the caregiver contributes greatly to assisting the individual needs of the dependent person and is hence the subject and performer of health care actions<sup>(12)</sup>. A caregiver is someone related or not to the care recipient who is able to meet their needs and assist them in activities of daily living<sup>(13)</sup>.

Such considerations justify the importance of studying the subject. Given that, this study sought to answer the following question: How does the family member/caregiver perceive the assistance to home care provided by health professionals to his/her relative/care recipient with chronic or terminal diseases? This study is relevant because identifying such perceptions can help the health care team rethink their practice by taking into consideration the possibility of a closer approximation to their social environment, i.e., the household. Furthermore, it can provide both the family member/caregiver and the health care team with a better understanding of the process of critically ill patients, such coma patients.

Thus, the present study aimed to analyze family members'/caregivers' perceptions about domiciliary hospitalization of people with chronic or terminal illnesses receiving care from health professionals.

## METHODS

This study uses a qualitative approach based on a deeper understanding of the universe of the different meanings of phenomena in the social world. The qualitative approach unveils experiences, narratives and social facts in the light of the subjectivation processes inherent to the patients involved<sup>(14)</sup>. The adoption of this approach is justified by its compatibility with the proposed objectives, that is, to seize the immaterial dimensions of the research participants' meanings and perceptions regarding home care based on their concrete experiences of taking care of their relatives/patients.

The study was conducted in the city of Guanambi, Bahia, Brazil, from March to April 2014. The municipality of Guanambi is located in Southwestern Bahia, which is 796 km away from the capital. The municipality has 78,801 inhabitants<sup>(15)</sup> and a semi-arid climate and is a regional center of economy, health and education<sup>(16)</sup>. The research setting was the Guanambi Regional Hospital (*Hospital Regional de Guanambi – HRG*). It is a general public hospital affiliated with the campus XII of the Bahia State University (*Universidade do Estado da Bahia – Uneb*) for curricular internships of Nursing students and is a microregional referral health care center with 140 beds. It is a reference for the care of high-risk pregnancies, urgencies and emergencies for 31 municipalities. It features specialized and follow-up outpatient clinics and counts on human and technological resources for the provision of medium complexity medical care in the medical, surgical, pediatric and obstetric clinics. It also provides adult ICU, Neonatal ICU and Neurosurgery<sup>(17)</sup>.

This setting was chosen due to the multidisciplinary team of the home care program linked to the Guanambi Regional Hospital, which has been providing this kind of care since 2012 seeking to adopt mechanisms to improve the quality of the care provided to users of the Unified Health System (SUS) and reduce hospitalizations in large public hospitals<sup>(17)</sup>. At the time the study was conducted the program had 60 patients enrolled and all of them had reduced mobility and the majority had sequelae caused by noncommunicable diseases (NCDs).

Data were collected through semi-structured interviews, which are considered ideal for data collection in qualitative studies as they allow to evoke ways of thinking and acting based on the participants' private experiences<sup>(18)</sup>. The interviews were carried out with family members/caregivers in a private room at the households. The interviews were recorded and then transcribed verbatim. They lasted 30 minutes each and were held after authorization by the study participants. The reliability of the statements was preserved. There was interaction between interviewee and interviewer.

Family members/caregivers of people with chronic or terminal illnesses were included in the study after receiving verbal invitation to participate and information about the research objectives. The participants should be 18 years old or older, be the main caregiver in the household, spouse or first or second degree relative, live in the city where the study was carried out and be a caregiver of people with chronic or terminal illnesses with hospitalization length of more than 30 days. Participants who did not meet the inclusion criteria and those who did not wish to participate in the study were not included. However, it should be noted that no one refused to participate in the study. Thus, the final sample comprised eight family members/caregivers. Sampling was finished after data saturation was achieved<sup>(19)</sup>.

The interviews were carried out using a questionnaire with a set of questions related to the identification of each interviewee (family member/caregiver) in the first questions and sex, age, marital status, education, occupation and household income. After that, the participants were asked the research question related to the objective of the study: How do you perceive the domiciliary hospitalization assistance provided by health care professionals to your relative/care recipient?

The content analysis method was used to treat the data<sup>(20)</sup>. The analysis was divided into three stages: pre-analysis, material exploration, and treatment and interpretation of results. Thorough horizontal and vertical reading of the interviews was able to identify the core meanings (satisfaction, care, support, acknowledgement, commitment, household, health care team, limited mobility), which allowed for the identification of the study category: Family members'/caregivers' perceptions about domiciliary hospitalization (DH) of people dependent on care.

This study was approved by the Research Ethics Committee of the Bahia State University (*Universidade do Estado da Bahia - UNEB*) (Approval No. 558.697). The participants signed an informed consent form. Names of precious stones were used to refer to and differ family members/caregivers and preserve the identification of the study participants.

## RESULTS AND DISCUSSION

This section will present the identification of family members/caregivers and then discuss the category Family members'/caregivers' perceptions about domiciliary hospitalization (DH) of people dependent on care as a space for relationships, interactions and quality of life.

### Identification of family members/caregivers

Most family members/caregivers were women. With regard to age, six were over 50 years old and two were under 50 years old. As for marital status, five interviewees were married, one reported being single and two were widowed. Regarding education, one participant reported being illiterate, four had incomplete primary education, one had incomplete secondary education and two had completed secondary education. In regard to occupation, five participants were retired, one was a pensioner, one was self-employed, and one was a student. As for monthly household income, eight participants earned up to three minimum wages.

### Family members'/caregivers' perceptions about domiciliary hospitalization (DH) of people dependent on care.

The category Family members'/caregivers' perceptions about domiciliary hospitalization (DH) of people dependent on care presents the family member/caregiver in the context of DH as an interactive link between the person with chronic or terminal illness and the health care team.

Based on the knowledge of their experiences in DH health professionals can effectively contribute to innovative education and health care practices that include those involved in this process<sup>(21)</sup>.

The following statement shows that the interviewees see DH as a "merit", or a "godsend":

*"[...] I feel very satisfied, I am very proud to have this merit, to have these girls here, in my house, every day... To tell the truth, I never thought of that... But God saw I needed it!" (TURQUOISE)*

This statement allows to infer that the interviewee does not seem to know her rights as a citizen as she does not recognize that it is the government's duty to guarantee the right to DH. The SUS principle of universality states that the individual is entitled to access to all public health services<sup>(22)</sup>. A godsend may be characterized as a privilege to her and is therefore related to receiving care from the professional team rather than the structure and organization of the system itself. The next statements continue complimenting the service received:

*"[...] I think that everyone who comes here takes good care, sees that she is at home; there is nothing better than that for a child [...]. In the hospital, it is much more difficult [...]. This domiciliary hospitalization thing was the best thing." (CRYSTAL)*

*"[...] We are satisfied, my wife and I. So... we are even thankful for this job and all the effort put by the government to ensure this domiciliary hospitalization. It is a very good job." (DIAMOND)*

The patients served by the DH program were older adults who spent most of their lives without receiving this comprehensive and structured care within the Health Care Networks, as recommended by Ordinance No. 963/2013, which redefines home care in the Unified Health System<sup>(13)</sup>. Therefore, they are not used to this type of care. The statements also point out a positive perception demonstrated by the satisfaction with home care, which, for them, means comfort, tranquility, and guarantee of a humanized and personalized service focused on the real needs of people requiring permanent care.

In a study conducted in 2014 with DH patients, the evaluation of family members/caregivers is consistent with the findings of the present study. The respondents stated that home care means protection and improves quality of life based on humanized care provided by professionals<sup>(23)</sup>.

As an innovative strategy, the implementation of DH requires reflection regarding the organization of practices and should take into consideration the people involved, the comprehensiveness of care, the resources needed to provide this type of care, and the articulation with other health care services. Thus, this type of care should be seen as an important strategy and not just an alternative offered to people who are transferred as soon as possible to their homes for recovery, rehabilitation or palliative care. In fact, it should be seen as a space for comprehensive and humanized care<sup>(24)</sup>.

It should be noted that palliative care is defined by the World Health Organization (WHO) as actions offered to people with diseases that no longer respond to curative treatment. Thus, the control of pain and other symptoms, the attention to psychological issues and the emotional and social support are the most relevant issues and are mainly aimed at improving the quality of life of patients and their families<sup>(25)</sup>.

The participants' statements show that they realize the importance of multi-professional home care as they welcome the team that gives them comfort, emotional support, rehabilitation, nursing care and nutritional guidance. This is what the following statements show:

*"[...] she misses it. Just today she was asking: Where is the nurse who did not come here? I said, 'oh, mom, tomorrow. They come twice a week'. Even she feels good about your work." (CRYSTAL)*

*"I liked it. They, the professionals, are very good, polite, meet the injection schedule... I cannot complain [...] I am very satisfied... It feels great, being treated at home is great." (SAPPHIRE)*

*"[...] they are good professionals. They arrive, put bandages on, and talk to him. They all come and do their jobs. He likes it a lot. They prescribe, request tests, the doctor comes, the other come [...] talk to him." (RUBY)*

*"[...] there was something she could not eat. [...] Then the nutritionist came, [...] the physical therapist came too... I have all the guidelines. Sometimes I forget something, then they come in during the week, I ask them, and they teach me what I should do. So, thanks God, it was very good for me." (EMERALD)*

The interviewees' statements show that caring is shared between family members/caregivers and health workers, which represents a possibility of establishing horizontal relationships that value other people who are not part of the health care team but who are also active participants in the process of caring in the context of DH. These are relevant aspects of DH that should be highlighted and that are different from the reality of hospital practice, which is mainly centered on the physician. It is known that the construction of singular therapeutic projects is far from being achieved, but there have been advancements. The family members/caregivers interviewed explained that their experience with home care is very positive. They acknowledge that this type of care makes a difference and recognize the importance of visits by the health care team for both the family and people with chronic or terminal illness.

The health care team provides home care in a different way because their involvement is different from that in the hospital, and the family likes to be cared for at home, not only because of the comfort provided, but also because of the differentiated care they get<sup>(26)</sup>.

Thus, as the family receives professional guidance to provide daily care to the patient, they feel calmer and tend to reduce their stress level<sup>(27)</sup>.

The family members/caregivers also stated that being visited by the health care team in the DH program is an important advantage given the easy access to care; in addition, people with chronic or terminal illness do not need to get around, thereby avoiding tiredness and enabling time and resource optimization. The fragments of the statements below show these findings:

*“The domiciliary hospitalization was a very good project that the government implemented, because we cannot afford to be always getting around with him. We have no car. [...] Imagine taking a child to the physical therapist in the morning; to the speech therapist in the afternoon; and then to draw blood... So, I mean... it would be a lot more tiresome to take the child here and there, so I think it helps a lot!” (DIAMOND)*

*“[...] It is a very good advantage because... You do not have to... Right now, I cannot be going to the Regional with her like this [...] Then, I have domiciliary hospitalization, the professionals come to our home. [...] If you need, you can call them. I have called them several times and they have answered.” (EMERALD)*

In this regard, the DH service can be characterized as an indirect support to the social and economic limitations of family members/caregivers, thus contributing to eliminating expenses and saving time that would be spent on the displacement of people with chronic or terminal illnesses. Other potentially positive aspects of this type of care refer to the reduction of long waiting times in an emergency care service, i.e., there is an easy access to the health care team that is a reference for the person requiring permanent care, which makes access to emergency and urgency care somewhat easy<sup>(28)</sup>.

With regard to the human resources of the DH program of the city where this study took place, some family members/caregivers of chronically or terminally ill patients stated that there is a lack of some professionals or certain services that would help or facilitate patients' access to complementary services. This is what we can infer from the following statements:

*“[...] I believe that if there were more professionals, so that other professionals who are already at work could have more time for each patient, it would be better. [...] We miss some other professionals, [...] like a psychologist, and other fields, right? Then it would be very good.” (DIAMOND)*

*“I think it is good the way it is. But I think there should be more doctors.” (EMERALD)*

*“There should be more professionals [because] there are not so many... There are few professionals and too many patients. I think it is not enough. [...]” (AMETHYST)*

Despite the satisfaction with the type of care provided to the community, family members/caregivers feel the need to increase the number of caregivers and to include other professionals. These findings are consistent with those of a study conducted with 14 family members/caregivers in the home care program of a public hospital in a municipality of Bahia. Semi-structured interviews used in the study revealed a lack of professionals such as psychologists<sup>(24)</sup>.

Corroborating the statements previously presented, both people who require permanent care and the family members/caregivers involved in DH show interest in expanding the home care team, which requires more professionals committed to this type of care. This expansion refers to both the number of professionals and the access to other specialties whose knowledge and practices also build health care in different dimensions and are beyond the biomedical model of care, such as psychosocial care, which favors the provision of comprehensive health care to this population group<sup>(29)</sup>.

The present study confirms the relevance of the National Health Promotion Policy<sup>(9)</sup> and the Home Care guidelines<sup>(8)</sup> as it demonstrates that access to different levels of health care within the Health Care Network may be – especially for patients in greater need for care – an experience of a complex health-disease condition with dignity and respect for the uniqueness of patients' physical conditions and the social vicissitudes of families.

The limitations of the present study are related to the fact that it was carried out in a single health care facility with its own singularities. However, it is important to highlight that it can support the development of public policies, not only in the municipality where this study took place, but also in other places in the country.

The present study is impactful as it collaborates in the construction of evidence on the importance of domiciliary hospitalization and demonstrates that the quality of the care delivered by health professionals is based on the needs of users taking into account the specificity of the morbidity profile of the patient and thereby providing comfort and quality of life. Based on this concrete experience, domiciliary hospitalization proves to be a care option focused on the humanization of care and the connection with other health care facilities within the Health Care Network (in this case, the hospital network), which allows strengthening the Home Care policy guidelines, which, among other aspects, seek to promote the emergence of other non-traditional approaches to health care<sup>(30)</sup>.

## FINAL CONSIDERATIONS

The perceptions revealed by family members/caregivers of people with chronic or terminal illness about DH indicate: satisfaction with the care delivered by the home care team; improvement of the relationship and interaction between

the family member/caregiver, the person requiring care and the health team professional through a differentiated care that is based on respect for the individuality and uniqueness of each family; and there is no need to get around with the care-recipient. However, the statements also show that the service offered to these patients seems to be a favor to them, not a right of access to the public health service. In addition, the interviewees find the number of professionals insufficient and there is a need to expand the team. Therefore, the team should be sensitized about the relevance of discussing with family members/caregivers their rights as citizens.

Caring involves relationships between people in the process of mutual learning and subjectivation. Therefore, further studies should analyze the place occupied by family members/caregivers in this triad, how much they interfere in the care provided and how the entry of health professionals in the family relations can change family roles and new care arrangements.

## CONFLICTS OF INTEREST

The authors declare that there is no conflict of interest regarding the publication of this study.

## CONTRIBUTIONS

All authors contributed to the study conception; data collection, organization, analysis and interpretation; and the writing of the manuscript and the final version for publication.

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