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Original Article

Perceptions and feelings of the family member/caregiver expressed before the patient on home care

Percepções e sentimentos do familiar/cuidador expressos diante do ente em internação domiciliar

Percepciones y sentimientos de la familia/cuidador expresos delante del pariente en atención domiciliaria

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Objective: to analyze the perceptions and feelings expressed by relatives regarding the patient undergoing home care**. Methods:** this is a descriptive and qualitative study, with data collection carried out through semi-structured interviews at home, developed with fourteen family members of patients assisted by a home care company. Data were organized by content analysis technique**. Results:** perceptions and feelings expressed were: insecurity, fear, anxiety, worry, feelings of deprivation of liberty and at the same time, gratitude for the care, comfort, safety and proximity to care control, preferring the admitted patients at home and rated the care as satisfactory. **Conclusion:** home care should be seen as an innovative humanized care modality that aims to reverse the logic of work of health professionals, which is not limited to meet the clinical needs of patients, but also provide necessary support to the families involved.
Descriptors: Family Nursing; Caregivers; Home Nursing.

Objetivos: analisar as percepções e sentimentos expressos pelos familiares em relação ao paciente submetido a internação domiciliar. **Métodos:** estudo descritivo com abordagem qualitativa, a coleta de dados foi realizada por meio de entrevista semiestruturada no domicílio, desenvolvido com quatorze familiares de pacientes atendidos por uma empresa de *home care.* Os dados foram organizados por meio da Técnica de Análise de Conteúdo. **Resultados:** as percepções e sentimentos expressos foram: insegurança, medo, ansiedade, preocupação, sentimentos de privação da liberdade e ao mesmo tempo, gratidão pela assistência, conforto, segurança e proximidade para o controle do cuidado. Preferindo os entes internados no domicílio e avaliaram o cuidado como satisfatório. **Conclusão:** a internação domiciliar deve ser vista como uma modalidade de atenção humanizada inovadora que visa inverter a lógica de atuação dos profissionais de saúde, que não se limita a atender apenas às necessidades clínicas dos pacientes, mas também fornecer suporte necessário aos familiares envolvidos.
Descritores: Enfermagem Familiar; Cuidadores; Assistência Domiciliar.

Objetivos: analizar percepciones y sentimientos expresados por los familiares en relación al paciente sometido a la atención domiciliaria. **Métodos**: estudio descriptivo, cualitativo, cuya recolección de datos se realizó a través de entrevistas semi-estructuradas en el hogar, desarrollado con catorce familiares de pacientes atendidos por una empresa de atención domiciliaria. Datos fueron organizados por la técnica de análisis de contenido. **Resultados:** percepciones y sentimientos expresados fueron: inseguridad, miedo, ansiedad, preocupación, sentimientos de privación de libertad y, al mismo tiempo, gratitud por la atención, comodidad, seguridad y proximidad a controlar cuidadosamente. Prefiriendo ser admitidos en domicilio y evaluaron la atención como satisfactoria. **Conclusión**: la atención domiciliaria debe ser vista como innovadora modalidad de atención humanizada que tiene como objetivo revertir la lógica del labor de los profesionales de salud, que no se limita sólo a satisfacer las necesidades clínicas de pacientes, sino también proporcionan apoyo necesario a las familias involucradas.
Descriptores: Enfermería de la Familia; Cuidadores; Atención Domiciliaria de Salud.

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Introduction

Home care has been growing gradually in Brazil. The home care has health services with therapeutic supports made at home.

In this mode, the care is held by a multidisciplinary team who performs personal care; medication care; healing wounds, pressure ulcers, and ostomies; support for other diagnostic and therapeutic measures. Besides the use of high nosocomial technology and other hospital resources necessary for sustaining life, the patient still has the support of family and caregivers in the continuity of care and the comfort at home[1-2].

As the eligibility criteria for Home Care, there is the classification table of the Brazilian Association to Homecare Medical Companies that evaluates and classifies care complexity, in which, through a sum of points, it determines if the patients have an hospitalization profile and their respective complexity. This complexity is flexible, that is, regardless of the complexity the patient is classified, varying initially for admission to home care.

The hospitalized patients are classified according to the level of complexity, where each level corresponds to the way in which the service is performed and may change according to the clinical case of the patient. The classification is: low complexity, with monthly medical visit, a weekly nurse, the multidisciplinary team with eight monthly visits and from nursing technician care six hours a day; medium complexity, the medical visit is biweekly, a weekly nurse, the multidisciplinary team with ten monthly visits and nursing technician for twelve hours a day; and high complexity, with a weekly medical visits, a weekly nurse, multidisciplinary team of fourteen monthly visits and nursing technician for twenty-four hours[2].

The home care is intended for stable individuals, temporary or permanent disability patients with a complex clinical condition that require attention in full or part time and specialized technology, with a multidisciplinary team monitoring, consisting of doctors, nurses, physiotherapists, nutritionists, psychologists, speech therapists and nursing staff.

The nursing and medical visits can vary according to the history of the patient, receiving as many visits as required if there are clinical events.

In home care, the presence of family acting is essential, helping for rehabilitation, helping the health team to perform any need or change of the health status of the patient. In this sense, there is the importance of the team to include the family in this care, bringing them closer to the family, creating links, providing technical support, guidance and constant monitoring to caregivers, so they feel safe in the caring role[3].

When facing home care, the nurse faces interests undergoing understanding of feelings involved and the hope of the family in the patient's recovery. Among the challenges the nurse has during this care model, there are to maintain emotional balance and provide effective assistance both to the patient and the family[4].

Thus, considering the complexity that involves home care, the question is: What is the meaning for the family to keep the patient under home care?

We believe that this study is of great importance because it is a form of the current job, in which the nurses and their team develop a job with greater autonomy and have a significant role in patient recovery. This study also may be useful to health professionals on the theme of deepening knowledge of the investigation by providing reflections that resonate in clinical practice through innovative actions, and may also be a source for further research.

Thus, this study aims to analyze the perception and family feelings for the patient undergoing home care.

Method

This is a descriptive study with a qualitative approach. The descriptive research aims at identifying,

recording and analysis of the characteristics, factors or variables that relate to the phenomenon or process, using standard techniques of data collection, presenting in an organized way the information about the assisted patients or data produced by information services[5].

A qualitative research is an interpretative technique that is concerned with aspects of reality that are unable to investigate by quantitative means, and can be understood and explained in the dynamics of social relationships in which the researcher develops concepts, ideas, and insights from patterns found in data[6].

The research was conducted from November to December 2014, in a private home care asisting health insurances, in which the home care program is developed since 2011.

Data collection was conducted through semi-structured interviews with closed and open questions individually, the family´s home as their availability, after clarification of the research and agreement of the participants, by signing the Instrument of Informed Consent Form.

There were 14 family members included who were responsible for patients in home care and participating in the care and their routines, selected because they meet the following inclusion criteria: responsible family member that performs great care of patients admitted to home, over 18 years old, accepting to participate in the study and signing an informed consent form. The relatives of patients admitted for less than a month in the home care program and family members who are not responsible for the direct care or inpatient monitoring were excluded.

The guiding question of the study was "What are your feelings about home care of your family member?'.

The interviews were recorded, with the permission of the participants, using an electronic device with subsequent transcription of the speeches.

Data were organized by content analysis technique, which point out the following steps: pre-analysis, material exploration, and treatment of results[7].

First, there was the transcript of the interview, in which the recorded interviews were written in the word program; then, a floating reading of the participants´ speeches of the research was done, highlighting the most relevant data for the study. After this step, the Excel program was used for categorizing according to common characteristics data. Finally, the elements were classified by their similarities and association. There was a spelling character of the language corrections made in the speeches without affecting the sense.

To ensure confidentiality, respondents were identified by capital letters F1 to F14, symbolizing the respondent and the family bond.

The project was approved by the Ethics Committee in Research of the Salgado de Oliveira University of Goiás issued a favorable opinion number 856,815, according to principles of Resolution 466/12.

Results

The study included 14 families responsible for patient assisted at home Care.

As for the family caregiver profile, it was found that most were children, followed by female spouse, higher proportion of family income with 1-3 times the minimum wage, which 72.0% reaches fewer than six minimum wages, with own resident, more than half of respondents have higher education level, 57.0% are older than 61, mostly retirees, in which, 71.0% also have chronic diseases. It was noted that the family caregiver has advanced age and consequently physical and emotional limitations, needing essential care assistance at home for the patient.

Family members are organized in the care according to the level of complexity classified by home care, with most of the treated patients classified as medium and high complexity. According to the

Care Plan, following the protocol of by the company, only patients classified as "high complexity" are assisted by 24 hours nursing technicians, and in other complexities family members assume the full role of caregiver in patient care.

Patients are totally dependent for daily life activities, requiring constant monitoring as well as intensive care, such as patients on oxygen therapy, requiring time, patience and availability of the family, a complex task that is linked directly to the recovery and quality life of the patient.

Among the chronic degenerative diseases that motivated home care and reliance on technology, the is Alzheimer's. Given the above, it is noted that the level of complexity, aspects of the disease, age and level of dependence directly influence the organization and routine of the family in patient care.

Thus, when questioned if there was rotation in the provision of care, most of them replied that there was rotation: some do it with siblings, children and others with nursing technicians. As for the relatives of patients classified as high complexity, they responded that there was no rotation of care, only aid in the mobilization of the patient that required greater physical effort.

Perceptions and feelings expressed by the family

By analyzing the statements and dialogic movement within the interviews, family members expressed different kinds of feelings such as insecurity, fear, anxiety, worry, feelings of deprivation of liberty and at the same time, gratitude for the care, comfort, safety with the service and proximity with the staff to care control.

In the statements of respondents F6, F7, F8 and F9, they show fear and insecurity to keep the patient with disabling diseases and aggravated at home. In the case of any urgent situation or emergency, it is noted that there is a concern of caregivers in the assistance not arriving on time. *At the beginning, I had a lot of fear, insecurity, and I did not want to leave him at home because he was breathing on mechanical ventilation* (F6 daughter). *When there are complications, I'm afraid there's no time to the assistance to arrive* (F7 daughter). *I'm afraid he will die at home* (F8 wife). *The downside of the hospital at home is that the doctor is no direct as in the hospital* (F9 daughter).

In this study, all family members showed some situation of change in routines, which generated fear and insecurity, requiring adaptations and deprivation after home care of the patient, according to the testimonies: *It is a double feeling, before that disease my father was a very actice, and then he got sick and that shook us very much, due to the drastic change the person who until a year ago was going up on the roof' and now he can barely get out of bed, so it's a feeling of loss, lack* (F3 son). *Sometimes you can not get out, have a more active social life, then you have to restrict it* (F4 daughter). *First we had to adapt the space, improve the physical environment, also had to adapt to diapers, she did not use them and started using, she fed and now she stopped eating, and adapt my schedule to be with her... It was an adaptation and a new world that was not part of my life* (F_5 granddaughter). *I had to change my work schedule and close the shop to be full-time* (F6 daughter).

The lines F3, F4, F5 and F6 show that besides passing by the changes caused by the disease process the family is still facing changes in routine, adaptations of the physical environment and hours.

Family members believe that without home care and health insurance fully fund the home care program, according to the testimony, it would not be possible to keep the patient at home because home care needs hospital professional guidelines, plus the high cost compared to household income, concerning the assistance and technological resources, as the following lines stated: *It was great that home care, thank God we have it, if not, I do not know what I would do* (F1 daughter). *I did not know that existed, it is all new... it's good! The doctor said that her situation was serious and that she had to stay at home, for her and for us it would be better and would be more affordable* (F2 sister). *In our specific case, with another big advantage with our health insurance, home care had a cost almost zero, then we do not have to question because we know the cost would be if it were private* (F3 son).

When asked about which preference the respondents have between hospital admission or

home care, all 14 family members said that they preferred being admitted at home. They highlighted the advantages of home care, including the representation of that care in the home means protection, and feeling more at ease as long as the patient can stay at home. *You take care of your family member together is one thing, and take care of him in the distance is completely different, because you are seeing, watching, and also we know that Hospitalization has much risk of infection. It is better for the patient, he feels safer with the family, the same for the family for treatment and we know that if it were not for this treatment at home, she would not be alive, she would not resist staying at the hospital so long* (F_9 daughter). *Much better, we are always in control of care, if she were in the hospital toda, she would not be alive* (F11 daughter). *Not good, but I prefer it than the hospital, we are here watching him all the time* (F2 sister). *I think it is very good my grandmother being at home, she is closer to us, there is also a comfort for me, because we get wear going to the hospital and I think she feels better, though she had Alzheimer, her level of awareness is low, but from the moment we started talking to her that we would leave the hospital, her high pressure was began to normalize. I believe that even the little consciousness, she managed to grasp: it's better at home* (F5 granddaughter).

It was identified that there is a parallel with the hospital admission, how the negative of the hospital is seen, highlighting the risk of exposure to infection, that respondents reported. The F9 and F11 respondents associate hospital to death.

From the perspective of caregivers, home care is important in carrying out of the closer monitoring of the patient present at all times of care, controlling, and more freedom, and also providing comfort, protection, warmth, factors that improve the quality of life of the patient and help in rehabilitation. *It is closer monitoring, a caring, it seems that we have more security* (F1 daughter). *I take care better at home and for him it is better also, more comfortable, not carrying him or moving him* (F12 wife).

As one of the quality aspects, it is noteworthy to consider the services that are offered and the assessment of their level of satisfaction. We can identify that regarding the satisfaction of home care services, all respondents are satisfied with the inpatient program.

It was observed in the reports the satisfaction with the care provided at patients´ home assisted in the program, demonstrating the importance of this care model. *We know there are competent people looking after the welfare of my father, I was kind of carefree with the treatment that is being given to him* (F3 son). *With the health team, we get quiet, because we can count on them, we have them to help us* (F_2 sister). *I am very grateful to the program and thank God for its existence* (F6 daughter).

Discussion

Patients who are assisted by home care are composed of elderly with chronic diseases, aggravated by the senescence, causing functional limitations and disabilities depending on the third-party care and specialized care. It is noticed that home care has been directed mainly to this population.

The data obtained about gender reveals the woman's role as a provider of traditional care of the health of children, parents, and spouses. Historically, the woman has always been responsible for the care. Despite all the social changes in new roles assumed by women, although it is expected that women assume this function.

The sociodemographic profile of the caregiver is extremely important, it is through him that the characteristics of the involved family members can be traced and analyzed to understand the individual way of how each family faces difficulties and how they behave before the hospitalization process.

The degree of kinship influences the choice of who will take care, the closer the family ties, the more chances this person will be responsible for patient care.

Caregiver refers to love as motivation to care, the woman is socially inserted into the mother´s role, and her care is seen as natural. The idea of the

obligation to children care for their parents is also based on the belief of the good relationship between the generations, it is the moral duty of responsibility, gratitude retribution, reciprocity, friendship and love than they received[8].

The patient can not always choose the caregiver, especially when the patient is a closer relative, and most of the time the caregiver is not prepared, insecure or afraid to take this role[9].

The responsibility of care restricts activities, bringing worry, fear and insecurity, and places the family in the absence of emotional support[10]. It is essential that professionals understand that it is a noble job, but a complex and tedious task, causing physical and emotional exhaustion, changing family dynamics and being surrounded by different feelings and paradoxical[9].

Is important the family unity so that care can be shared reducing the physical and emotional burden of the main caregiver.

It is also observed that there is privation in the life of the caregiver, requiring dedication and sacrifices, giving up personal and professional activities and the postponement of life projects. These changes are necessary, but compromises the mental health of individuals who care because they ignore their needs at the expense of patient´s convenience.

The caregiver is a great human being driven by love that is available to provide care to someone dependent, requiring special care to perform daily life activities[11].

Prolonged hospitalization causes major changes in the patient´s lifestyle, moving him apart from his social network and his personal effects, and having the risk of hospital infection[12].

We noted that, even not being in health care, they have knowledge that the hospital brings a greater risk of infection because of increased exposure to pathogens.

They emphasize that when exercised with quality, home care can bring many benefits both for patients and for families, providing a better recovery and rehabilitation, reduction in hospital admissions, and performing a more humane, safe and effective care, basing the care in the reality the patient live[13].

The family function is to help in the rehabilitation of the patient and detect difficulties and needs helping the team[3]. Knowing this, the health team must add the family in their care plan providing security to take the caregiver´s role.

Family perception of care about the quality of home care showed that they are satisfied, but with some criticism regarding the lack of some specialties and suggestions as certain services that would help or facilitate the accessibility of the patient to complementary services[14].

The emphasis of giving the maintenance of functional capacity are strategies aimed at postponing death as much as possible, slowing disease outcomes with quality of life, autonomy and independence[15].

The involvement demonstrated through the speeches causes to believe in a process of humanized work by the staff of the studied unit.

Conclusion

From the results, it was found that family caregivers are mostly women, with advanced age, retired, earning 1-3 minimum wages and have chronic diseases, complicating the role of the main caregiver, becoming indispensable a sharing care.

In care organization, most of them shared the tasks, reducing the physical, emotional and financial burden.

The Home Care is a trend that is becoming more common, and it is mainly growing because the increase in the elderly with chronic diseases, especially Alzheimer's.

Perceptions and feelings expressed by family members were several, noticing the impact that

the disease causes especially when home care, demonstrating diverse and contradictory feelings about the relative hospitalized at home, feelings such as deprivation of liberty, insecurity, availability and security with the staff by a closer assisting and monitoring the health status, protection, satisfaction and some optimism.

As for home care, a positive perception of the family regarding this type of service was prevailed, supported by the high level of satisfaction, highlighting the crucial role of health professionals in the success of this type of hospitalization.

In this way, this study is very important for health professionals working, or those that may act on this new health care model because they will be able to understand better the characteristics, needs and family expectations to provide more targeted assistance, adapting behavior to the reality of each family to provide quality care, considering the humanization, the host, creating bonds and communication as they are the ones who are in closer contact with the patient and should be a greater ally of the health team members.

Thus, Home Care should be seen as a way of humane and innovative care that aims to reverse the activation logic of health professionals, not limited only to the patient but extended to his family. The team has a very important role in home care, as a support for the family, when, meets with emotional difficulties, assisting to the wishes of the family members involved.

Collaborations

Fogaça NJ and Carvalho MM contributed to creat this work, collection, organization, analysis, data interpretation, article writing and final version to be published. Montefusco SRA contributed to job creation, article writing and final approval of the version to be published.

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