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PERCEPTION OF PEOPLE WITH CHRONIC DISEASES ABOUT HOSPITALIZATION

PERCEPÇÃO DE PESSOAS COM DOENÇA CRÔNICA ACERCA DA INTERNAÇÃO HOSPITALAR

PERCEPCIÓN DE PERSONAS CON ENFERMEDAD CRÓNICA SOBRE LA HOSPITALIZACIÓN

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ABSTRACT

Objective: to know the perception of people with chronic diseases about hospitalization. ***Method:*** descriptive, exploratory, qualitative approach. Fifteen people with chronic diseases were interviewed in the Medical and Surgical Clinics of a University Hospital of Southern Brazil. The data were produced from a script that subsidized the semi-structured interviews, recorded, transcribed and analyzed by the technique of Content Analysis in the Category Analysis category. ***Results:*** elucidated categories that reveal the elaboration of meanings about the process of illness, the understanding and resignification of feelings and the recognition of needs for care. ***Conclusion:*** considered to be relevant to identify the perception about hospital admission, as it provides to increase the quality of care and health education actions. ***Descriptors***: Chronic Disease; Hospitalization; Nursing; Diabetes Mellitus.

RESUMO

***Objetivo*:** conhecer a percepção de pessoas com doenças crônicas acerca da internação. ***Método*:** estudo descritivo, exploratório, de abordagem qualitativa. Foram entrevistadas 15 pessoas com doenças crônicas nas Clínicas Médicas e Cirúrgicas de um Hospital Universitário do Sul do Brasil. Os dados foram produzidos a partir de um roteiro que subsidiou as entrevistas semiestruturadas, gravadas, transcritas e analisadas pela técnica de Análise de Conteúdo, na modalidade Análise Categorial. ***Resultados*:** foram elucidadas as categorias que desvelam a elaboração de significados acerca do processo de adoecimento, da compreensão e ressignificação de sentimentos e do reconhecimento de necessidades para o cuidado. ***Conclusão*:** considerou ser relevante identificar a percepção acerca da internação hospitalar, pois proporciona ampliar a qualidade do cuidado e das ações de educação em saúde. ***Descritores*:** Hospitalização; Enfermagem; Doença Crônica; Diabetes Mellitus.

RESUMEN

Objetivo: conocer la percepción de las personas con enfermedades crónicas en la hospitalización. ***Método:*** descriptivo, exploratorio, cualitativo. Fueron entrevistados 15 personas con crónicas clínicas médicas y quirúrgicas de un Hospital Universitario en el sur de Brasil. Los datos fueron producidos a partir de un guión que subvencionado las entrevistas semiestructuradas, grabado, transcrito y analizado por la técnica de Análisis de Contenido en modo de Análisis Categorial. ***Resultados:*** fueron conocidas las categorías que revelan la elaboración de significados acerca de la enfermedad proceso, comprensión y sentimientos y reconocimiento re significación de las necesidades de atención. ***Conclusión:*** considerar pertinentes identificar la percepción sobre la hospitalización que ofrece para ampliar la calidad de las iniciativas de Educación de cuidado y salud. ***Descriptores*:** Hospitalización; Enfermería; Enfermedad Crónica; Diabetes Mellitus.

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INTRODUCTION

Non-transmittable chronic diseases (NTCDs) are considered a global problem due to the imminent health risk.[1] They are directly and indirectly responsible for about 70% of deaths in Brazil, and in most cases are due to diseases motivated by low adherence to non-drug treatments and the low effectiveness of health promotion actions.[2-4]

The development of chronic diseases is usually slow, with periods of remission and exacerbation, and most of the time the cure is non-existent. The discovery of a NTCD implies changes in lifestyle, and it is necessary to develop adaptive skills for healthy living.[2-4] These adaptations involve changes in daily life, such as drug treatment, follow-up with health professionals and periodic examinations, practicing physical activity, adhering to a healthy eating plan, and developing the skills to care for oneself according to the specific needs of each chronic illness.[5]

Thus, living harmoniously with chronic diseases implies experiencing the process of acceptance of the disease, which consists in the perception, respect and coping with the reality of their condition.[6] However, many people find it difficult to follow the recommended treatment due to their complexity and influence of the socio-historical-cultural context, and the low adherence to chronic disease treatments presents itself as a problem can generate health complications, frequent hospitalizations and increase in the expenses of health systems.[1-2]

Thus, the need to better understand the process of living with a chronic disease in times of destabilization emerges, and the present study is guided by the following research questions: How do people perceive hospitalization as a result of their chronic diseases? How do they recognize the influence of life and health habits on the occurrence of hospitalization? How do you understand caring for yourself and your illness in the long run?

Given the magnitude of the problems related to NTCD, such as the high hospital admission rate, the high financial, emotional and social costs that these diseases cause, the lack of adherence to the treatments and the impact on the health-disease process, this study aimed to:

- Know the perception of people with chronic diseases about hospitalization.

METHOD

This study is the product of a Nursing Graduation Course Completion Work of the Federal University of Santa Catarina, conducted in 2013. It is an exploratory descriptive study, with a qualitative approach.7 The study was developed in medical hospitalization units and of a university hospital in Southern Brazil. Data were collected from August to October 2013, in a hospital environment, in private areas, in which semi-structured interviews were conducted, guided by a script with questions related to the participants' perceptions about hospital admission.

The study sample consisted of 15 hospitalized patients who met the following inclusion criteria: Age above 18 years; Having the cognitive and communication capacity preserved, according to subjective evaluation of the researchers, and possessing one or more chronic diseases, from which were selected Diabetes Mellitus (DM), Systemic Arterial Hypertension (SAH) and / or Chronic Obstructive Pulmonary Disease (COPD). These diseases were chosen due to their epidemiological relevance and also to the fact that the majority of the clients hospitalized at the research site had these diseases, and the hospital admission units are state referrals for the health care of people with these diseases.

As for the characterization of the participants of the research, nine were men and six were women. Nine were married, three widowed, and three unmarried. The age range ranged from 26 and 78 years. Regarding schooling: one person never studied; eight did not finish elementary school; three completed primary school; two completed secondary school and one completed higher education. With regard to the presence of chronic diseases: two participants had only one of the chronic diseases selected for the study, and the others had an association of two or three diseases. The group of participants was heterogeneous in relation to the time of illness, ranging from four days to 28 years. Seven had their first hospitalization and eight had previously been hospitalized (from one to four previous hospitalizations).

The interviews were recorded and, later transcribed, being analyzed based on the following steps: a) apprehension - in this stage, the interviews are read and the relevant elements are identified; B) synthesis - this step occurs by means of line-by-line coding and definition of pre-categories and c) theorizing about the findings.[8-9]

The research obeyed the ethical aspects, according to Resolution n. 466/2012 of the National Health Council[10], and was approved by the Research Ethics Committee of the Federal University of Santa Catarina under no. 19509913.1.0000.0121 and opinion no. 367.842 / 2013. Participants were informed about their nature, objectives, methods, expected benefits, potential risks, and their voluntary participation, authorized by signing the Free and Informed Consent Form. To ensure confidentiality and anonymity, participants' names were replaced by codes, drawn using the letter E, followed by the sequential number of the interviews. To represent his disease, P was used for COPD, D for DM and H for SAH (ex: E01PD, ie Interviewee 01, with COPD and DM).

The present research was not sponsored for its accomplishment, but, it was supported by the National Council for Scientific and Technological Development (CNPq) and the Coordination for the Improvement of Higher Education Personnel (Capes), through scholarships at undergraduate level, Doctorate and research productivity. It was emphasized that there is no conflict of interest of the authors in the accomplishment of this study.

RESULTS

The analysis of the data allowed the elaboration of three categories: The aggravation of the disease and the lack of necessary health care; Feelings experienced during hospitalization and Positive expectations regarding hospitalization, which will be presented as follows:

♦ The worsening of the disease and the lack of necessary health care

The carelessness was identified as the main motivator of hospitalization, being responsible for the worsening of the disease and the worsening of the health situation, being justified by the difficulty of adherence to prescribed medication and behavioral treatments, considering them too strict to be followed. In some situations, hospital admission was recognized as a consequence of the 'natural and not very preventable' worsening of the disease, being inherent to the process of living with a chronic disease. This perception was very clear in people with COPD, who considered the worsening respiratory condition and dyspnea as manifestations that are not easily avoidable due to the influence of external factors, such as changes in the climate, not depending exclusively on self care. Such a position was tied to the attempt to minimize individual responsibility for self-care, as evidenced by the following statements:

> *It changed the weather and then began to give me this tiredness and I could not work right anymore. When I do, I have to stop and rest. When I walked a little and I had to rest, I could not work and could not lower, because it made me dizzy, it made me cough ... (E11PH)*

> *Everyone I know who has diabetes also develops kidney problems, it's just the same ... (E07DH)*

> *I went to a doctor down in the center. She made a list of what I had to eat and what I did not have to eat. But, I said to the doctor, "Doctor, if I go after this, I'm going to starve!" So I do not diet, I do not think it has to be that way, that's not what would change my illness. (E09DH)*

People with DM,more often recognized, the lack of necessary health care, linking hospitalization directly to the way they were living. They affirmed that they were aware of the possible complications due to the diseases, but, the neglect of their own health involved the late identification of the signs and symptoms of aggravation, perceiving the worsening of the disease only when the manifestations were accentuated and practically unviable daily activities:

> *I think my carelessness, my poor diet and my lack of whimsy have contributed to the worsening of the disease. If I had been more careful from the start, I would not be here in this situation. (E08DH)*

> *I had a little hole in my foot, but I did not pay attention. So, it all happened here on my foot [end necrosis], so, I came to stop here. Now, I have to amputate four fingers. (E09DH)*

> *I was feeling very weak. He walked a little, rested, walked a little, rested. I could no longer do my activities. Only then did I come in the emergency and my son was together, then they intubated me ... I was bad .... So, here I am. (E01PD)*

♦ Feelings experienced during hospitalization

The hospitalization process was referred to as a mobilizer of negative feelings, among them fear, discomfort, suffering and guilt. These were reported in different ways by people, and for those who lived the first hospitalization, was found that the fear related to the discovery of the seriousness of the diseases and the repercussions they could cause to health, beyond the uncertainty related to the future and new therapeutic needs. For those who have experienced previous hospitalizations, the fear was related to previous experiences and to the fear of

new episodes of pain arising from treatment, moments of suffering and grief.

The discomfort related to the need to adapt to the hospital and inpatient routines was recurrent, being always accompanied by reports that the living in the home would be more pleasant and comfortable. Hospital admission was also reported as causing suffering linked to separation of family and work or leisure activities and by the uncertainty of family well-being during the period of hospitalization.

It was identified that the guilty feeling was linked to the recognition of the lack of care with him and the non-accomplishment of the therapeutic recommendations, leading to the aggravation of the disease. The guilt was also very much related to the remoteness of the home and family, to the 'inconvenience' caused to the companions, as well as the increase in family expenses with transportation and meals of the companion, which could have been avoided with greater adherence to the treatments.

> *I was not here, I was not home. I'm stubborn, I do not like hospital. I suffered a lot from the hospitalization in which I amputed that leg. I do not tell my wife, but I want to die at home now, I do not want to die in the hospital. I suffered a lot of pain in this leg, I took three morphine injections and I did not want to know more about it, I think, it would be much better in my house. (E15DH)*
>
> *Here I get a little tense and scared, I wonder what my house will be like? My children? My grandson? Then, I'm kind of apprehensive ... (E06DH)*
>
> *I'm going through all this now, but if I had been careful from the start, I would not be here. I was hospitalized for a whole month, and the complications of the disease remain. Besides, messing up my whole life, I cannot make a commitment, I'm depending on others ... (P08DH)*
>
> *I have a great fear of hospitalization. That's why, I even gave up my cigarette. I have gathered enough information, I ask everyone who appears. I am worried about the feet, as they say that the feet of those who have diabetes are very sensitive. (E04D)*

♦ Positive expectations regarding hospitalization

Acceptance and adaptation were experienced as part of the hospitalization process, being difficult because it was permeated by conflicting feelings, such as the need for patience and conformation, maturation and the ability to overcome adversity and face with good humor. Even hospitalization was a stressor in people's daily lives, there were reports of increased faith and hope for improved health status after hospital discharge, as well as the perception of support from family and friends in this process.

> *You have to have patience, first of all, patience. If you despair, then, complicate everything! So you have to be calm, because calm makes the rest possible. (P03PH)*
>
> *I'm hospitalized and I'm going to do what? You have to conform. It's not because today I lost five fingers that I'm going to start crying! You have to party and play, because it's a life thing, right? (P09DH)*
>
> *Now, thank God, little by little I'm getting better, because I'm sure God does not want this for me and I do not even want to! So, a little bit I'm getting better ... of course, quite, very carefully. (P02DH)*
>
> *I could see how much we are loved among family, friends and even the church brothers. Sometimes we do not realize how much people are valued by these people, because our daily lives are very busy and sometimes we do not realize it. (P12DH)*

Expectations regarding hospitalization, such as the greater adherence to treatment after discharge, the possibility of recovery, the improvement of pain and changes in lifestyle and health were observed from the participants' speeches. Hospital admission promoted reflection on daily attitudes and brought to light the risks of complications and worsening of health, leading to the re-signification of processes, bringing the future expectation of greater adherence to therapeutics.

> *Discovering diabetes has made me now have time discipline in my diet, I started to know myself more, to value myself and even to love me. I ate a lot of stuff overdone and then went on for a long time without eating. At no point in my life have I made this process that I am doing now, eating every three hours. (P04D)*
>
> *Now, I have learned even more to care for myself, to value my life, my body more. After being hospitalized, I noticed the work that goes on and the work it gives to others as well. I think I've learned a lot. It served to correct some things, to learn, for the maturing of the perception of things. (P02DH)*

DISCUSSION

The occurrence of hospital admissions may be associated with several factors, [11] however, in this study, there was a correlation with the low adherence to the treatment and the lack of follow-up of the therapeutic recommendations, being influenced by the individual understanding of

the recommendations and by the complexity of the therapeutic regimen in Capacity.

In this study, COPD patients associated the cause of hospitalization, mainly with worsening of the disease and environmental changes. This finding corroborates the study carried out in 17 university hospitals in France, which sought to identify characteristics associated with chronic cough and The production of sputum in patients with COPD has found that exacerbations of symptoms are frequent during periods of climate change and that severe cases require hospitalization.[12]

Studies indicate that many people with chronic diseases, among them DM, have undergone several hospitalizations, being responsible for higher costs to the health system, indicating the need for care and management interventions, aimed at intensifying prevention and health promotion actions with a view To increase the quality of care.[1-2,13]

The period of hospitalization can be recognized as a propitious moment to establish health education actions that increase the theoretical and practical knowledge of each patient, favoring the establishment of new therapeutic goals that subsidize self-care at home.[14] However, a study indicates that there are many difficulties of implementing the proposal in face of the conditions of work currently experienced in public hospitals and the need for multi-professional action in the socialization of knowledge through health education actions.[14]

Thus, it is necessary to understand the characteristics of the individuals for the development of specific interventions that meet their needs, increasing the quality of care and avoiding unnecessary hospitalizations and health aggravations, highlighting the need for multiprofessional and multisectoral actions for the prevention and control of Diseases and human suffering.[11,15]

The results indicate that the hospitalization was perceived by the people as an important event in their lives, which generally favors a rethinking of the way they were taking care of their health, being a permanent life experience.[5,16] This period of reflection often occurred after Acceptance of health status and adaptation to the hospital environment, and it is a propitious moment for people with chronic diseases to propose greater adherence to treatment and changes in lifestyle.[5,16]

In this study, we observed that most of the participants were motivated to take care of themselves, but, due to the methodological design, it was not possible to verify if the desire for change materialized after hospital discharge. This fact requires further investigation, considering that adherence to the treatment of people with chronic diseases, among them DM, becomes a difficult process, requiring family, social and health support.[1-2,17-19]

CONCLUSION

Hospital admission is a significant moment in people's lives, when expectations regarding their illness emerge, becoming a propitious moment for the performance of the multiprofessional health team, with emphasis on health education actions. Increasing the quality of care can contribute greatly to the health of people with chronic diseases, both in basic care when identifying possible reasons and aggravations for hospitalization, and in hospital admission, helping in understanding the patient's expectations regarding hospitalization and in the Development of an educational process, which leads to greater adherence to treatment.

We believe it is relevant to know our clients, their fears, concerns and expectations so, as to offer them a quality care, that contemplates the different needs of the attention. We also noticed that the lack of orientation leads to difficulty in perceiving the worsening of the disease, leading them to seek health care in a later period.

It is concluded that more studies are needed regarding this issue, considering the magnitude of the high expenditures in the public health budget, the implications that chronic diseases bring to today's society and the complications caused in people's lives.

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