

SOCIAL REPRESENTATIONS OF PATIENTS WITH ARTERIAL HYPERTENSION ABOUT THE DISEASE: THE DISCOURSE OF THE COLLECTIVE SUBJECT*

REPRESENTAÇÕES SOCIAIS DE PORTADORES DE HIPERTENSÃO ARTERIAL SOBRE A DOENÇA: O DISCURSO DO SUJEITO COLETIVO

REPRESENTACIONES SOCIALES DE PORTADORES DE HIPERTENSIÓN ARTERIAL SOBRE LA ENFERMEDAD: EL DISCURSO DEL SUJETO COLECTIVO

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ABSTRACT

This article aims to analyse the representations of patients with arterial hypertension, users of basic health care services, about the disease and their self-care routines. Semi-structured interviews were carried out; data was organized using the discourse of the collective subject and interpreted by the theory of social representations. The results revealed the patients' insufficient information about the disease, its control and treatment. Patients acknowledge that hypertension is a serious illness that may have serious consequences if not treated. Health care services' structural deficiencies contribute to discourage users from participating in health promotion activities. The study results indicate the need for increasing health care activities aiming to inform patients about a conscious control of hypertension.

Keywords: Hypertension; Nursing Care; Basic Health Unit.

RESUMO

O objetivo com este artigo foi analisar as representações dos usuários de serviços básicos de saúde portadores de hipertensão arterial sobre a doença e a maneira como se cuidam. Utilizou-se a entrevista semiestruturada para os portadores da doença. Os dados foram organizados utilizando-se a técnica do Discurso do Sujeito Coletivo e a teoria das representações sociais para sua interpretação. Os resultados revelaram conhecimento insuficiente dos usuários sobre a hipertensão arterial e os meios para o controle e tratamento da doença. Reconhecem a hipertensão como uma patologia grave, que pode trazer grandes consequências quando não tratada. As dificuldades estruturais dos serviços contribuem para desmotivar o usuário a participar de ações de promoção em saúde. Tais resultados indicam a necessidade de intensificação das ações assistenciais que sensibilizem os portadores da doença para a busca pelo controle consciente da hipertensão.

Palavras-chave: Hipertensão; Cuidados de Enfermagem; Unidade Básica de Saúde.

RESUMEN

Este artículo tiene como objetivo analizar las representaciones de los usuarios de servicios básicos de salud portadores de hipertensión arterial sobre la enfermedad y la forma cómo se cuidan. Utilizamos la entrevista semiestructurada para estos pacientes y los datos recogidos fueron organizados según la técnica del sujeto colectivo e interpretados según la teoría de las representaciones sociales. Los resultados mostraron conocimiento insuficiente de hipertensión arterial, medios de control y tratamiento de la enfermedad. Reconocen que la hipertensión es una patología grave que puede traer serias consecuencias cuando no se trata. Las dificultades estructurales de los servicios contribuyen a desmotivar la participación de los usuarios en acciones de promoción de la salud. Esos resultados indican la necesidad de intensificar acciones asistenciales que alerten a estos pacientes y los incentiven a buscar control consciente de la hipertensión.

Palabras clave: Hipertensión; Cuidados de Enfermería; Unidad Básica de Salud.

INTRODUCTION

Arterial hypertension is today considered one of the most significant risk factors for cardiovascular, cerebrovascular and renal diseases and a serious public health problem worldwide. It accounts for at least 40% of deaths due to stroke, 25% of deaths from coronary heart disease and, when associated with diabetes mellitus, 50% of cases of end-stage renal disease. In Brazil, there are approximately 17 million people with hypertension. This number represents 35% of the population aged over 40 years old¹.

According to the database of the Unified Health System (Datusus) in the state of Minas Gerais there are 789,211 hypertensive patients. In the city of Juiz de Fora, 24,483 hypertensive patients are registered; data from the Primary Care Information System (Siab) reveal that only 17,639 are monitored by the local health services^{2,3}.

One of the biggest challenges in the control of hypertension is the asymptomatic nature of the disease. Overall, it has been observed that, except in cases requiring frequent monitoring, basic health services users seek assistance only when symptoms appear. Users diagnosed with hypertension and needing larger amounts of medications are eligible to those provided by the health system, under the condition that they participate in the activities proposed by the health service, such as educational groups and health visits.

Hypertension care and control represent a challenge when patients need to achieve goals for blood pressure control levels. As users do not have an adequate knowledge of hypertensive diseases and care, this causes feelings of despondency towards the educational and physical activities proposed by the health services; moreover the number of participants is low regarding the number of registrations at the health unit⁴.

From this perspective, it is important to discuss co-responsibility and the co-construction of autonomy in care and to present this factor as relevant and essential in health care. This means that, in seeking the co-construction of patient and professional autonomy, the organization of the clinical and collective functions should be expanded alongside the management and health care models. Consequently, health care essential objectives would be health production and the co-construction of the reflective capacity and autonomous care of the individuals involved in these processes – workers and users⁵.

Whereas the population chosen as study subjects has not yet been dealt with from this perspective – since the work process is still centred on the professionals' actions – the present research sought to address hypertension based on the assessment of those who experience it in their daily lives as patients.

OBJECTIVE

The present study proposes to investigate a group of hypertensive patients in primary health care units, observing hypertension care practices and aiming to analyse their social representations on hypertension and their health care practices.

METHODOLOGY

The survey was carried out in Juiz de Fora, state of Minas Gerais, with twenty-five hypertensive patients, eighteen female and seven males aged between 21 and 78 years old, all primary health care users. The oldest diagnostic was made 36 year ago, while the newest was two years ago; most female respondents were housewives and housemaids and the male participants were construction workers. The inclusion criteria were: to have been diagnosed with hypertensive disease for over a year, to be registered in the health unit for hypertensive care, to be 18 years of age or older; to agree to participate in the study after reading and signing the Informed Consent Form (ICF). The exclusion criteria were: to have been diagnosed with hypertension for less than a year, not registered in the health unit for hypertensive care, to be under 18 years of age and to disagree with the ICF.

Semi-structured interviews containing open questions related to the patients' knowledge about hypertension and its treatment and control were performed. The interviews were carried out between October and December 2007, after the signature of the informed consent form. The project was approved by the Research Ethics Committee of the Anna Nery School of Nursing of the Federal University of Rio de Janeiro (UFRJ), under the committee's Official Opinion No. 062/07. Any additional information given by the subjects was recorded in a research notebook

The interviews were conducted by the researcher, recorded on tape, transcribed and organized using QualiQuantSoft® application; at the end of this stage a speech synthesis called the Discourse of the Collective Subject (DCS) was built. To construct this discourse, the following tools were used: Key Expressions (KEs) – segments of the discourse, continuous or non-continuous, that should be highlighted and whose function is to show the contents of an answer to a research question, revealing the essence of the statement that refers to the core idea (CI); Core Ideas (CIs) – name or linguistic expression that describes, concisely and accurately, the meaning of key expressions (KEs); Discourse of the Collective Subject (DCS) – meeting, on a single homogeneous speech synthesis, of key expressions that have the same core idea. The DCS is a way to express directly the social representation of certain collective subject. After the identification of CIs and based on KEs, those presenting the same meaning, equal meaning or complementary meaning are grouped into categories; these categories are

called to express, in the best way possible, same meaning Core Ideas in order to construct DCS, which is a method of processing statements created to express the collective thinking⁶.

After the narratives were organized, the theory of Social Representations was applied for the analysis of the research findings.

RESULTS AND DISCUSSION

Two themes guided the representations of *disease* and *care* by the users. The first was the representation of the disease and the second refers to the representation of daily self-care. The latter is the object of the present analysis.

On the topic "representations on hypertensive disease", the patients developed concepts with the following core ideas: hypertension as the disease of fear, life-threatening disease, causes sequelae, poses limits to life, requires care and changes in lifestyle and habits.

REPRESENTATIONS OF HYPERTENSION BY THOSE SUFFERING FROM THE DISEASE

The Core Idea "Hypertension as a disease of fear, a life-threatening disease, causes sequelae and poses limits to life" was elaborated by 72% of the participants (18 interviewees) as can be seen in DCS 1:

It's a condition that I have and if I don't take care of it, it can kill me. It means worry. It was a shock! I was really scared and sought treatment immediately (...) what a scare. It is life threatening because if it gets too high, I can have a heart attack, a stroke. So it must be treated, it should be taken seriously because of the sequelae. I take my medicines, but even so, we have to take a lot of care. Ah! A very difficult thing it is, a lot of work, and when it comes, it's dreadful! We have a hard time! It is also a nuisance because it limits us in many things; the high blood pressure distresses us much (...) and we get worried because it is a dangerous disease, that people when they have it, they are in danger. Ah! to me, is the worst thing (...) I do not like it, no, but I take care, because this is hereditary, I think it will not go away, so you have to take care (...) because I had nothing (...) after I found out I had high blood pressure, it ended. I do not like it, I think it's horrible. Many things I can't do because it already holds me back (...) I'm afraid to have a stroke, I'll go or I'll be a nuisance to others. I'm afraid. I felt I had to take care. It is a problem, isn't it? You can't eat a lot of things. It's a health problem. It's very upsetting. It's annoying, it's anxiety, it's stress.

One lives trying to avert or delay the moment of one's death. When we fall ill or identify any changes in our physical

integrity, we feel threatened and begin to fear further that possibility. The disease process leads to two paths: fighting to live, preferably without the disease, or give up and wait for the end. The fear of dying accompanies human beings, even though we know that someday it will happen; throughout our existence, we try to "negotiate" with the possibility of death^{7,8}.

The people who built that discourse believe that being hypertensive is having a disease that brings risk to human existence, therefore, a serious disease. They argue that they live with a big problem; a nuisance and a concern with the possibility of irreversible sequelae that threaten their life at all times.

For some people, the presence of a disease – even a controllable one as in the case of non-communicable diseases – seems to have an impact in their daily routine, as it relates to the possibility of living and the complications resulting from the pathology. The occurrence of disease is, at the same time, the more private and the more social of events affecting humans; it can be considered as an attack, an ordeal, a mistake or a choice, governed by a code of understanding the symptom that takes into account numerous social dimensions⁹.

The users' narratives revealed that they feel threatened by the possibility of a stroke, a heart attack, or even death if they do not give hypertension importance. Despite the need for controlling the disease as the only way to prolong life, people's everyday life is threatened by the uncertainties of the disease sequelae. The label "a chronic disease patient" imposes a limit, which restricts normal living. Thus, however much they worry and want to be well they live under the threat of the harm the disease can cause.

Another representation present at this DCS is fear; the fear of hypertension reported by the patients in this study, is directly related to some of the disease's complications: stroke, dependence on others, and fear of becoming an invalid.

Hypertension is considered among hypertensive patients as a disease that causes concern, fear and anger. In developing a study about living with hypertension, the authors show that more than half of the participants assessed life negatively after the diagnosis of the disease¹⁰.

Many representations that people have about their illnesses are independent of medical knowledge. Thus, experiencing a disease is to have a conflicted relationship with the social because the person with a disease will feel ill when it fails to perform activities belonging to the context in which they live. On the other hand, it is a way to self-knowledge once the individual learns to overcome its handicap in order to cope with the illness¹¹.

In experiencing the process of being diagnosed with hypertension, the user is able to give it a new meaning, not only in-

formation, but especially the concrete experience of living the disease signs and symptoms or even its consequences. Getting sick means being in touch with the possibility of the disease; it means living with diseases that hitherto were mere possibilities⁹.

The users that elaborated this DCS also reveal that chronic disease is the main factor to develop positive attitudes to health care. They know that once diagnosed with hypertension, they will need to change old habits because of the sequelae the disease can cause. They claim that even with all the difficulties to control the disease, controlling it is better than living with sequelae resulting from poorly controlled blood pressure, whereas, when the disease is “uncontrolled”, the consequences are even worse, given the constant physical discomfort, often incompatible with the will to live.

It should be considered, however, that hypertension is a disease that requires changes in lifestyle, when the latter is not consistent with health care. The representations of hypertension as a nuisance call attention to the perception that vulnerability to an uncontrolled disease is the common thread in the search for disease stabilization.

Another representation elaborated by users on hypertension belongs to the second core idea: “Hypertension as a disease that requires care and changes in lifestyle”. The DCS 2 discloses this representation:

I don't know what it means because I never felt anything, thanks God! Ah! I don't worry too much, I take the medicine and I think the medicine will control it, but I know it's dangerous, if one forgets to take the medicine, it may surprise you, rise. Ah! for me, it was the same thing, it was nothing, it was nothing (...) I think that if they had told me it was a bad disease... but this?... It's easy! Ah! I just avoid eating too much fat. I came because they told me to because it's good to have a look (...) but I don't feel ill, don't feel anything ... for me, it's normal, nothing to complain about, no, it feels normal (...) Don't have headache, neck pain, I feel nothing. It is total change of behaviour (...) advice we can't always follow. It's total change indeed, of food, medicine and lifestyle.

For the research subjects that elaborated this speech, hypertension is not a disease that brings difficulties to everyday life. The meaning and significance of disease control or treatment include trusting in the intake of medicines and adopting healthier eating habits, such as reducing amounts of salt and fat; according to the people that elaborated this DCS such actions are not difficult to be implemented in their daily routine. Hypertension is, therefore, a condition that requires changes in lifestyle, without interfering negatively on people's quality of life. Despite claiming that it is necessary to implement radical

lifestyle changes and that such changes are not always easy, the context is not seen as a deterrent to leading a normal life.

Some researchers on the theme believe that each individual has a notion of life and being healthy that relates to the way they relate to their everyday life:

Health depends a lot on the perception of each individual about quality of life, well-being, being able to perform one's role in society. Therefore, to the individual with artery hypertension, health can be visualized as the understanding of one's limitations and of the potentialities of living with hypertension. Finding a healthy way of living with the disease and trying to live a better quality life depends on the hypertensive individual perception and acceptance. The process of accepting and living with a chronic disease, in this case hypertension, includes the acceptance of limits, the searching of new ways for daily living, of acquiring new abilities and changing habits to enable a healthier living¹².

This way of representing the disease enables the establishment of an important stance on control/care actions; on one hand, the patient believes on the possibility of control through medication and changes in lifestyle, on the other, he/she seems unaware or does not want to know about the disease's complications. Such assumption is grounded on the users' speeches when the disease's consequences are not explicitly mentioned in the narratives; this DCS demonstrates that with the absence of signs and symptoms patients delay to take responsibility for their own health care or are discouraged to do so.

The representation in this DCS is based on the concept that hypertension is a common and controllable disease and less severe if compared to other conditions; it makes it less significant in relation to what it is and easier and more comfortable to control daily. Often, denial or even resistance to follow the professionals' advice are used as a means not to accept the condition of sufferer of a serious illness.

The characteristics of patients with hypertension – their representation of the disease and how to take care of themselves – are crucial for hypertension control. In this case, health behaviour is determined by the users' representation of their susceptibility to the disease, its seriousness and the benefits of and obstacles to treatment. The forms of disease control are not automatically accepted, but are evaluated by the patients taking as basic reference its consequences¹³.

The Ministry of Health emphasizes that lifestyle changes are fundamental during treatment process. Despite the undeniable evidence of the benefits of changes in lifestyle, a large section of the population has not incorporated the need to avoid the risk factors related to hypertension¹.

In relation to arterial hypertension control practices, it is observed that.

In asymptomatic patients, adherence to treatment mean temporary disciplines imposed and lived as disturbances in their way of life; it means rejecting the role of patient, when the patient wants to continue to represent [...] as an asymptomatic state, socially invisible and radically different from a disease condition¹⁴.

Adherence to treatment may happen after users understand their current and future health status, including the risk factors and treatment methods, so that, together with the healthcare team, they can develop strategies able to control the pathology. Counselling and health education activities must be understood as a process, not a finished product, in order to transform the individual and convince him/her of the importance of the patient involvement in the process of adherence to anti-hypertensive treatment.

Some researchers detected the same attitudes when discussing the issues surrounding adherence to HIV control therapy in the country. According to them, treatment adherence is one of the most important aspects surrounding HIV-infected patients, as therapeutic success depends on it. This context is seen daily among patients with hypertension and is a major obstacle to the disease control¹⁵.

The abruptness of the diagnosis of hypertension and the asymptomatic nature of the disease makes treatment adherence even more difficult. Health education should reinforce the positive activities undertaken by patients; it should be continuous in order to broaden the knowledge of these users about the importance of antihypertensive therapy, even in asymptomatic individuals¹⁶.

Individuals who participated in this study revealed that they feel comfortable and safe living with hypertension, even when aware that non-adherence to blood pressure control may contribute to its rise. The search for care and treatment is not triggered by possible symptoms but by the advice they receive from health care professionals on the importance of seeking health services to control arterial hypertension.

THE REPRESENTATIONS OF HYPERTENSIVE PATIENTS ABOUT SELF-CARE

On topic "representation on self-care", the users elaborated the following core ideas: an integrated care perspective: lifestyle changes as necessary to care; care seen only as medicine intake: the drug is the best care strategy; health care professional advice and its influence on the care of hypertensive patients.

The core idea under the title "integrated care perspective: lifestyle changes as necessary to care" was produced by 44% of the participants (11 respondents). This representation can be observed in DCS 5:

First thing: I avoid salt (...); I try not to eat anything with salt, what is a nuisance, because at home the food is almost salt less because of the blood pressure. I avoid fatty foods (...), I walk every day and I don't drink. I don't have a sedentary life (...) Ah! I do all the work (...) and I try to do things that I know will not do me harm (...) and I try to keep calm (...) I try to keep calmer (...), my blood pressure seems to be emotional. Sometimes I have a little mint tea to help calm me down (...) I try to lead a balanced life, avoiding what could increase my blood pressure. Now I start to (...) do things that help to stabilise my blood pressure and my health too (...) but all the food must be different, more balanced (...) and I normally manage, but there are some things... we have to walk (...) sometimes I use the treadmill when I have the time to spare (...). We have to exercise as well to help a little, besides the medicines.

In this DCS it is observed that by incorporating the importance of controlling hypertension through the proper use of medications and changes in lifestyle, patients are trying to improve their quality of life. In this narrative, those with hypertension seem to know the means to hypertension control. Even if they do not follow all actions necessary to control the disease, those actions mobilize forces to be seized and incorporated into their knowledge. The health care process is characterised by conflicts and worries about the future; it is made of actions that are not always easy to follow, but are recognized as necessary for quality of life.

The discovery of a disease in people's lives can be seen as a condition for overcoming themselves, providing opportunities for self-disclosure with possibilities for exploring potentialities¹⁷.

Under these aspects, the DCS 7 exposes the ways people go through until the development of attitudes for the control of hypertension. It was possible to visualize the three concepts of disease described by a researcher when discussing the topic. Firstly, the discovery of the disease makes people feel different; they have to change their habits and will no longer be able to live as those who are not hypertensive. Secondly, when the individual begins to accept the condition of patient with a chronic disease, such acceptance opens up new possibilities and conditions for a reorganization of life. Lastly, when the patients accept the facts and adhere to the disease treatment and control¹⁸.

The core idea under "Health care seen as medication intake only: medicines as the best health care strategy" was built

by 40% of the participants (10 respondents). This representation is transcribed in the DCS 6:

I have the control done as it should be and take the correct medicines (...); I take my medicine in the morning. I don't go without my medicine at all... if they don't give it to me I buy it. I don't go without my medicine, must take it? I take it (...).when I feel like ... funny, I make an appointment to check my blood pressure. I take my medicines, every morning and night. Today I didn't because I don't have it. Sometimes I take the medicine on my own account (...) and then when my blood pressure is high, I take it.

According to the study subjects, being patient with a chronic disease such as hypertension seems to be associated with a new normativity of life – to take the medication. The patients understand the value of medication when they have their blood pressure checked. Medications are still today the most effective treatment for arterial hypertension control; other complementary care actions are not a part of the context of many patients. This representation needs to be carefully considered: such approaches for controlling hypertension, should not lead hypertensive patients to an indiscriminate use antihypertensive drugs.

Medication was elected as the best strategy for the control of hypertension; users report that they cannot do without it and, if the medicines are not available through the health system, they arrange for other ways to get it. Although they believe in controlling the disease through antihypertensive drugs, the latter's function seems to be unclear to them, and they are often used incorrectly in instances of blood pressure changes. Many patients with hypertension wanting to control the condition resort to practices that may bring serious consequences.

Thus, when dealing with the users' ways of coping with the disease grounded on the use of antihypertensive drugs, it is opportune to refer to Moscovici, who, based on influences transmitted by the information embedded in social relations, draws attention to changes that representations about a particular social object can have throughout life. This is how new representations are re-elaborated, and others, on the contrary, can crystallize¹⁹.

A symbology developed by a researcher on medication as a significant means to control the disease states that:

The symbolic power of the medication may be related to the belief that it is a constant in the therapeutic scene, i.e., it should always be present when it comes to face the disease, understood as a basically organic reality. This belief suggests that to confront disease, health can only come from an object (such as the medication), that shall incorporate it, represent it, symbolize it²⁰.

It is important to highlight that hypertension problem should be appreciated by the patient. Some hypertensive patients feel healthy and do not see reasons to follow a continuous therapy, especially when some drugs cause unwanted or secondary effects. It is essential the patients understand that prevention of complications related to hypertensive disease runs through an effective control of the disease, and one of its main aspects is the drug therapy.

FINAL CONSIDERATIONS

As part of their daily management of chronic conditions diseases, patients elaborated representations which indicated that an essential part of the illness control was the use of antihypertensive drugs and the need for changes in lifestyle. However, the latter is not always integrated within their daily life.

Generally speaking, patients with hypertension have more access to information about the disease, which promotes the knowledge and the understanding on how to cope with it. Users are aware that the disease must be taken seriously and that treatment needs to be continuous if they want to avoid the complications it can cause. There is a gap, however, between the perception of hypertension and the patients' self-care ability. Even though patients with hypertension represent the disease as serious causing sequelae and limitations to life, they cannot associate this knowledge to a daily practice of health care.

The asymptomatic nature of the disease is the aspect that hinders the users' participation in health promotion activities offered by health professionals. The representations indicate that health professionals need to instruct users about the importance of daily care. It is important that professionals recognize that such aspect is valued by the patients who, although being victims of the lack of symptoms, are not aware of the process. To discuss with the users that aspect of hypertension is also an opportunity to instruct and lead them towards the control of the disease.

Another difficulty to treatment adherence is the comparison that users make between hypertension and other more serious diseases, such as some types of cancer, which are diagnosed in small proportion in health care units. The identification of this representation elaborated by the patient can be valued by the health professionals and incorporated into daily care. It could also direct discussions of the complications that can arise from a deficient blood pressure control. Furthermore, through the sharing of the different representations elaborated by the users, health professionals could facilitate reflections that would function as a stimulus for others to seek control of the disease.

In this sense, it is not enough that health care services provide the medications to control hypertension. It is necessary to know how to use them, and associate them to the un-

understanding of their meaning, so that actions are not reduced to the indiscriminate use of antihypertensive drugs. It will neither be enough the hiring of health care professionals without preparing them for the development of a more comprehensive set of actions.

For the study subjects and health care professionals, hypertension is a disease that messes life up, hinders actions and challenges their daily routine, especially when one takes into consideration the biggest challenge for the control of this condition – its asymptomatic nature. Considering the possibilities for its control and treatment, however, health care can and should be understood as a practice that frees the patient of the dependency on a professional. The patients trust that they can do better for themselves and, in the process, they can run into professionals involved and committed to quality of life and the social determinants.

Being a patient with a chronic disease such as hypertension, leads users and professionals to build ways to represent and explain the situation. This study revealed how they share thoughts and explanations that they display socially. The representations made by these individuals show the need to “polish” the phenomenon that threatens their everyday life and their social relationships. In elaborating these representations, it will be possible to build health care guided by scientific knowledge (reified universe), but also as an inherent value to the human condition.

The present study reiterates a health care model able to integrate the different knowledge needed for caring for the hypertensive patient. In practice, it means to think about running a network system in which health care needs are valued and not considered only as a demand on the Primary Health Units, the main entrance into the health system. It is, nevertheless, indispensable to recover and implement public health policies in the country to strengthen the bond of trust and resolvability between the one who cares (health care professional) and the care recipient (user). Such task should be performed with qualified and motivated human resources, plenty of quality supplies to support health care practice and financial resources to enable the health care agenda that best meets the needs of the local population.

The research findings expose the context studied. Such study, however, could be developed in other health units caring for people with hypertension, to enable the understanding of other contexts on the user’s perspective and contributing also to evaluate these services and actions.

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